

PM Testimony
Pages 163-251

AS I MENTIONED EARLIER TODAY, THE PEOPLE WHO WILL BE
PRESENTING
TESTIMONY DURING THIS NEXT HOUR AND FIFTEEN MINUTES ARE
INDIVIDUALS WHO REQUESTED TIME AND WERE ALOTTED TIME PRIOR
TO
THE MEETING.

WE'LL GO BACK TO GIVING EACH OF YOU THREE MINUTES FOR YOUR
COMMENTS.

I WOULD, IN FACT, ASK YOUR HELP IN TERMS OF KEEPING US ON
SCHEDULE THOUGH.

IT'S BEEN WONDERFUL THE WAY PEOPLE HAVE REALLY WORKED HARD
TO
FOCUS THEIR COMMENTS.

AND IT'S MUCH APPRECIATED.

MR. HARDING, WE'LL BEGIN WITH YOU, PLEASE.

>> THANK YOU.

GOOD AFTERNOON, EVERYBODY.

FIRST I WOULD LIKE TO SAY THANK YOU FOR JOINING US TODAY AND
PRESIDENT BUSH FOR FOLLOWING THROUGH WITH THE FREEDOM
INITIATIVE.

I'M DR. J. R. HARDING, AND I'M FROM THE GREAT STATE OF
FLORIDA.

I'M REPRESENTING NADD, OR THE NATIONAL ASSOCIATION OF
ALCOHOL,
DRUGS, AND DISABILITIES, AS WELL AS FLORIDA VOCATIONAL
REHABILITATION, AND MOST IMPORTANTLY, PEOPLE WITH
DISABILITIES.

I AM A LIFELONG PERSON WITH A DISABILITY.

AT AGE SIX I WAS DIAGNOSED WITH DYSLEXIA.

AT AGE 16 I SUFFERED FROM FIRST QUADRIPLÉGIA WALKING AWAY
FROM A

FIST FIGHT.

AT AGE 22 I WAS SUFFERING FROM ADDICTION AND NEEDED ASSISTANCE.

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AT AGE 32 I SUFFERED MY SECOND QUADRIPLÉGIA WITH TWO BROKEN LEGS

AND A BROKEN SHOULDER TO BOOT.

AT AGE 35, I HAVE A PH.D AND WORKING FOR THE STATE OF FLORIDA IN

VOCATIONAL REHABILITATION FOR NEARLY THREE YEARS.

FIRSTHAND FROM THIS LIFELONG HISTORY OF DISABILITY ISSUES AND

HEALTH KNOWLEDGE, I COME TO YOU WITH FOUR FOCUS TOPICS: ONE,

CARE; TWO, EMPLOYMENT; THREE, TRANSPORTATION; AND FOUR, TECHNOLOGY.

TO BUT BEFORE POINTING OUT THESE FEDERAL BARRIERS, I WOULD LIKE

YEARS STATE QUITE CLEARLY, FOR THE RECORD, THAT SINCE THE ELEVEN

YOUR OF THE PASSING OF THE ADA, OUR LIVES, IN CONJUNCTION WITH

LEADERSHIP, HAVE MADE SIGNIFICANT STRIDES.

BUT WE HAVE STILL A VERY LONG WAY TO GO.

IT SHOULD BE NOTED THAT OUR SOCIETY, TO INCLUDE THE COUNTY, MAINTAIN FEDERAL, STATE GOVERNMENTS, AND PRIVATE SECTORS, STILL

A NUMBER OF PHYSICAL, ATTITUDINAL, AND PROBLEMATIC BARRIERS, HANDICAPPING PERSONS WITH DISABILITIES.

CARE, THESE BARRIERS IN HEALTH CARE INCLUDE ACCESS TO PRIMARY

MENTAL HEALTH AND SUBSTANCE ABUSE TREATMENT.

WAS CASE IN POINT ON A PERSONAL NOTE, IN THE LATE 80'S WHEN I
TO SEEKING ASSISTANCE, IT WAS NECESSARY, AS AN OHIO RESIDENT,
RELOCATE TO THE STATE OF MINNESOTA TO FIND AN ACCESSIBLE
TREATMENT FACILITY.
ALL RIGHT.
THIS IS UNHEARD OF.
IT'S UNNECESSARY TO BE ABLE TO RELOCATE TO ANOTHER PLACE.

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PERSONS STILL TWELVE YEARS LATER AND INVOLVED WITH NADD, WE'VE BEEN
WORKING TO TEAR DOWN THOSE BARRIERS.
BUT STILL THE FACT IS, MOST PLACES DO NOT INCORPORATE
WITH DISABILITIES.
AND THUS, THE SOCIETY AS A WHOLE IS A CO-ENABLER, SPURRING
SUBSTANCE ABUSE AMONGST PERSONS WITH DISABILITIES.
TRANSPORTATION IS PROBABLY THE SINGLE LARGEST HANDICAPPING
BARRIER FOR PEOPLE WITH DISABILITIES.
THEY CANNOT GO TO SCHOOL.
THEY CANNOT HOLD JOBS.
THEY CANNOT VOTE.
LIFE THEY CANNOT GO TO THE DOCTOR, GO TO THE CHURCH, ENGAGE IN
IN GENERAL, IF THEY CANNOT GET THERE.
MUCH OF THE PUBLIC TRANSPORTATION SYSTEM TODAY IS STILL NOT
ACCESSIBLE.
THERE WHILE HERE IN D.C. AND IN THE CAPITOL, THERE IS THE METRO,

WELL IS THE ACCESS SYSTEM AND TRANSPORTATION THAT DOES OPERATE
-- AND BETTER THAN MOST STATES -- BUT UNFORTUNATELY,
TRANSPORTATION IS NOT RELIABLE AND NOT DEPENDABLE, AND SO
MOST OF OUR EFFORTS TO MAINSTREAM FOLKS AND ALLOW THEM TO HOLD
JOBS AND HAVE MEANINGFUL LIVES IS FOR NOT.
SINGLE EMPLOYMENT, VOCATIONAL REHABILITATION, IS PROBABLY THE
LARGEST EMPLOYMENT ENTITY IN THE COUNTRY.
THEY ARE FUNDED THROUGH THE REHABILITATION SERVICES
ADMINISTRATION, AS MOST OF YOU KNOW.
IT IS A UNIQUE PROGRAM BECAUSE IT ENABLES ANYONE TO BECOME

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WHATEVER HE OR SHE WOULD LIKE TO BE.
STATES, THE PREMISES IS INDIVIDUALIZED TRAINING, HOWEVER MOST
BY PARTICULARLY IN FLORIDA, WOULD ARGUE THAT THEY ARE SHACKLED
THE LEVEL OF FEDERAL REGULATIONS THAT GOVERN THE PROGRAM.
FEDERAL RESTRICTIONS DO NOT MATCH WITH THE INDIVIDUALIZED
EMPLOYMENT GOALS OF THE PROGRAM.
MONIES IN ADDITION, MOST OF THE PROGRAMS ARE OPERATED WITH 110
AND ARE STATE MATCHED.
THE AT THE VERY LEAST, FEDERAL RESTRICTIONS SHOULD ONLY APPLY TO
FEDERAL MONIES.
WE NEED YOUR ASSISTANCE TO ENABLE VENDOR PARTICIPATION,
SATISFACTION COMPETITION, AND DRIVE CUSTOMER CHOICE AND CUSTOMER

TO MEET WITH THESE INDIVIDUAL PROGRAMS.
TECHNOLOGY IS ONE OF THESE GREAT ENTITIES THAT WILL BREAK
DOWN
THE BARRIERS, THE ATTITUDINAL ISSUES, THE TRANSPORTATIONAL
ISSUES.
AND SO WE NEED YOUR HELP AS A PART OF THE FREEDOM INITIATIVE
TO
ENSURE THAT THE 56 CURRENT TECH ACTS BEING DEBATED ARE
FUNDED TO
IMPROVE THE AVAILABILITY OF ASSISTED SERVICES AND
TECHNOLOGIES
FOR PERSONS WITH DISABILITIES.

>> MR. HARDING, I APOLOGIZE FOR INTERRUPTING.

CAN I ASK YOU IF YOU WOULD BE ABLE TO WRAP UP, PLEASE?

>> YES.

>> THANK YOU.

>> IN CONCLUSION, I, AND OTHER PERSONS WITH DISABILITIES, IF
WE
CANNOT GET IN THE DOOR, USE THE SERVICES, AND DOES THE STAFF

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HAVE THE SENSITIVITY AND THE TRAINING TO PROPERLY INCLUDE
US,
THE EFFORT IS FOR NOT.
IN SHORT, WE NEED YOUR HELP TO FORCE THE VARIOUS SYSTEMS TO
WORK
TOGETHER TO OPEN THE DOORS FOR PERSONS WITH DISABILITIES,
NOT
CLOSE THEM UNNECESSARILY.
EVERYONE THE FEDERAL GOVERNMENT DOES BUSINESS WITH SHOULD BE
FORCED TO COMPLY WITH THE ADA AND THUS, AND THUS MEASURABLE
IMPROVEMENT TO HEALTH CARE, EMPLOYMENT, TRANSPORTATION,

GOVERNMENT SERVICES, AND THE DAILY ACTIVITIES WILL BE
IMPROVED.

THANK YOU.

>> THANK YOU VERY MUCH.

WE'RE JUST AT THE BEGINNING OF THIS PANEL.

BUT WE'VE HAD SEVERAL PEOPLE JOIN US THE DIAS.

INTRODUCE
AND I WOULD LIKE THEM TO GIVE THEM THE OPPORTUNITY TO

THEMSELVES VERY BRIEFLY BEFORE WE CONTINUE.

>> HI.

I'M LISA LARMON.

I'M WITH THE U.S. DEPARTMENT OF LABOR, OFFICE OF DISABILITY
EMPLOYMENT POLICY.

>> I'M LORETTA KING.

THE
I'VE BEEN HERE THE ENTIRE AFTERNOON AND LOOKING FORWARD TO

REMAINDER OF THE SESSION.

>> PAT MORISSEY, WITH THE ADMINISTRATION FOR CHILDREN OF
FAMILIES.

I'M
AND I'M THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES, AND

VERY PLEASED TO BE HERE.

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LATER
>> IF I CAN I ASK YOU, THOSE OF YOU WHO WILL BE TESTIFYING

ON HOLDING PURPLE CARDS, IF YOU WOULD ASSEMBLE IN THE BACK,
WE

WOULD MUCH APPRECIATE IT.

SPLITTING
I UNDERSTAND THAT YOU TWO GENTLEMAN ARE GOING TO BE

YOUR THREE MINUTES.

PLEASE PROCEED.

THANK YOU.

>> WE ARE BILL COFFELT, CO-CHAIR OF THE PARENT REPRESENTATIVE,

AND ROBERT SNIERSON, VICE CO-CHAIR OF SELF-ADVOCACY OF THE NATIONAL COALITION ON SELF-DETERMINATION.

PROMOTE WE ARE THE ONLY NATIONAL PARTNERSHIP OF PEOPLE WITH DISABILITIES, PARENTS, AND FAMILY MEMBERS, WHO WORK TO

FEDERAL POLICIES THAT SUPPORT THE FIVE PRINCIPLES OF SELF DETERMINATION AND THE VALUES OF THE COMMUNITY IMPARTIVE.

OUR ORGANIZATION WELCOMES THE OPPORTUNITY TO SHARE OUR VIEWS TODAY.

THE IT IS A BARRIER WHEN PEOPLE WITH DISABILITIES DO NOT HAVE FREEDOM TO EXERCISE THE SAME RIGHTS AS ALL CITIZENS AND TO ADVOCATE FOR THEMSELVES.

ALL PEOPLE ARE ENTITLED TO LIVE, WORK, AND PLAY IN THE COMMUNITY, REGARDLESS OF THE SEVERITY OF THEIR DISABILITY.

AUTHORITY TO WE BELIEVE PEOPLE WITH DISABILITIES SHOULD HAVE THE

SUPPORT. CONTROL WHATEVER SUM OF MONEY IS NEEDED FOR ONE'S OWN

PUBLIC THEY MUST BE AFFORDED THE OPPORTUNITY TO RESPONSIBLY USE

DOLLARS AS THEY ORGANIZE THEIR OWN RESOURCES.

WE RECOMMEND:

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>> INCREASED FISCAL INITIATIVES TO STATES TO SUPPORT

SELF-DETERMINATION AND CONSUMER CONTROL INITIATIVES, WHILE
DECREASING FISCAL INCENTIVES TO MAINTAIN INSTITUTIONS AND
SEGREGATED SETTINGS.

TO LEGISLATION> INITIATE, LOOK BEHIND SURVEY CONTRACTS, SIMILAR

SPECIALISTS THE ICFMR, FEDERAL MONITORING AND OVERSIGHT CONTRACT, WITH
DISABILITY SPECIALIST IN THE FIELD OF SURVEYING QUALITY
COMMUNITY SERVICES, AND HIRE ADDITIONAL CMSDD SURVEY

SERVICES. GROUNDED IN THE PHILOSOPHY OF HOME AND COMMUNITY-BASED

FAMILY >> CONSIDER THE LEGISLATION THAT WOULD ENABLE PAYMENTS TO
MEMBERS WHO ARE CARE GIVERS.

SUPPORT REPLACE SKILLED NURSING FACILITIES WITH HOME OPTIONS TO

CITIZENS WITH SIGNIFICANT MEDICAL NEEDS.

MAKE SOLVING THE WAGE AND RATE CRISIS A HIGH PRIORITY.

THIS THE NEW FREEDOM INITIATIVE WILL NEVER BE SUCCESSFUL UNLESS

BARRIER IS REMOVED AND THE CRISIS RESOLVED.

OFFICE >> INCREASED FUNDING FOR PROTECTION AND ADVOCACY AND AN

OF CIVIL RIGHTS PROGRAMS.

INCREASE >> INCREASE FEDERAL SUPPORT TO STATES TO DEVELOP AND

WORK SYSTEMS THAT DEFLECT INSTITUTIONALIZATION OF CHILDREN AND

A TOWARD HAVING EVERY CHILD HAVE THE OPPORTUNITY TO GROW UP IN

FAMILY.

CONTINUE THE COMMITMENT TO FUNDING OF THE TECH ACT PROGRAMS.

>> FINALLY, INCLUDE US IN THE PROCESS TO IMPLEMENT THE
RECOMMENDATIONS.

>> INCLUDE US IN THE PROCESS TO IMPLEMENT THE
RECOMMENDATIONS.

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>> THANK YOU.

>> THANK YOU, GENTLEMAN.

THANK YOU VERY MUCH.

MS. PUTNAM?

>> GOOD AFTERNOON.

I'M AN RN WHO WOULD LIKE TO ADVOCATE FOR A GROUP OF PEOPLE
IN

NURSING HOMES THAT HAVE RENAL DISEASE.

I WOULD LIKE TO PRESENT A PROGRAM THAT CAN EMPOWER THE
PROGRAMS

AND THEIR FAMILIES TO CHOOSE THE CARE THEY NEED TO DIRECT
THEIR

LIVES MORE INDEPENDENTLY.

THERE ARE MORE THAN 300,000 AMERICANS ON DIALYSIS.

AND 110,000 OF THEM ARE OVER THE AGE OF 65.

WITH THE AGING BABY BOOM GENERATION AND THE ESCALATION OF
DIABETES IN AMERICA, THIS NUMBER IS ABOUT TO DOUBLE.

DIABETES IS THE NUMBER ONE CAUSE OF KIDNEY FAILURE.

WHILE PATIENTS WHO ARE HEALTHIER AND ON DIALYSIS CAN LIVE
MORE

NORMAL LIVES IN THE COMMUNITY, THERE ARE THOSE WHO ARE MORE
FRAIL AND OFTEN GET CAUGHT IN A DOWNWARD SPIRAL WITH
EMERGENCY

ROOM VISITS FOR FLUID OVERLOAD AND HIGH POTASSIUM LEVELS,
LEADING TO SERIOUS INPATIENT CARE.

IF THEY ARE ABLE TO GET IMMEDIATE ATTENTION, THEIR COSTS ARE
MORE LIMITED.

STAYS MANY, HOWEVER, HAVE COMPLICATIONS CAUSING LONGER HOSPITAL
AND EVENTUAL TRANSFER TO SKILLED NURSING FACILITIES.
MUCH WITH THIS TRANSFER, THEIR PROSPECTS FOR RETURNING HOME ARE
LESS.

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HOMES THE ESRD PATIENT IS DIFFICULT FOR THE OVERBURDENED NURSING
TO KEEP UP WITH.
DIETS, THEY DON'T HAVE THE TIME TO MAKE SURE THAT THE SPECIAL
FLUID RESTRICTIONS, AND TIMELY MEDICATIONS WILL PREVENT
EMERGENCY HOSPITALIZATION AGAIN.
ICU CONGESTIVE HEART FAILURE AND ELECTROLYTE IMBALANCE CAUSING
EMISSIONS STARTS THE CYCLE ALL OVER AGAIN, IF THEY SURVIVE.
THE TRANSPORTATION, EITHER BY AMBULANCE OR A VAN SERVICE, FROM
NURSING HOME TO AN OUTSIDE CHRONIC DIALYSIS CENTER IS NEEDED
THREE TIMES A WEEK FOR THESE PATIENTS.
THIS IS VERY HARD ON OUR SICK PATIENTS.
HAVE I HAVE WITNESSED INJURIES UPON ARRIVAL TO THE CLINICS AND
PROPOSED KNOWN OF AUTO ACCIDENTS THAT HAVE OCCURRED. WITH OUR
PROGRAM, THESE TRANSPORTATION INJURIES AND COSTS CAN BE
ELIMINATED.
FOR WE ARE PROPOSING AN INTEGRATED MODEL OF CARE SPECIFICALLY
THE ESRD PATIENT.

NURSING,
IT STARTS WITH AN INITIAL PHASE THAT COMBINES SKILLED
ON SITE DIALYSIS, SPECIAL ESRD DIET, FLUID MANAGEMENT, AND
MEDICATION TIMING, ALL IN A SIX PERSON RESIDENTIAL SETTING.
FACILITY
AFTER THIS INITIAL PHASE, MOST OF THE RESIDENTS OF THIS
TO
SHOULD BE WELL ENOUGH TO HAVE RECEIVED SUFFICIENT TRAINING
RETURN TO THE COMMUNITY, WITH EITHER HOME DIALYSIS OR THEIR
ROAD
CHOICE OF OTHER NONMEDICAL RESIDENTIAL SETTINGS, OR ON THE
TO A KIDNEY TRANSPLANT.

MEDICARE CURRENTLY SPENDS AS MUCH ON HOSPITALIZATION FOR THE

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ESRD PATIENT AS THEY DO ON THE OUTPATIENT TREATMENTS.
DIALYSIS
WE ARE LOOKING AT A 30% COST SAVING ANNUALLY TO DECREASE THE
HOSPITALIZATION AND ELIMINATION OF TRANSPORTATION TO
CLINICS.

DIALYSIS
THE TALLEST BARRIER TO ACHIEVING THIS IS IN GETTING A
CLINIC CERTIFIED IN A 24 HOUR CARE SETTING.

CREATE A
TO MAKE OUR PROGRAM WORK, WE RECOMMEND THE FOLLOWING:

IN
NEW CERTIFICATION CATEGORY, INTEGRATED ESRD CARE FACILITY,

AND
WHICH FRAIL ESRD PATIENTS CAN RECEIVE DIALYSIS TREATMENTS

TWO,
SKILLED NURSING IN A SIX PERSON RESIDENTIAL SETTING; NUMBER

CREATE A NEW CERTIFICATION CATEGORY, SMALL ESRD FACILITY, IN

WHICH HEALTHIER ESRD PATIENTS CAN RECEIVE DIALYSIS IN A

NON-MEDICAL RESIDENTIAL CARE FACILITY;
NUMBER THREE, CONDUCT PILOT PROJECTS WITH A COMBINATION OF
MEDICARE, MEDICAID, AND OTHER AGENCIES AS APPROPRIATE TO
VERIFY
OF
COMMUNITY,
AND REDUCES MEDCIARE/MEDICAID ANNUAL COSTS BY 30%.
AS A NURSE CARING FOR ESRD PATIENTS LONG-TERM, MY PATIENTS
BECAME PART OF MY FAMILY.
I HAVE SEEN THIS CYCLE OF HOSPITALIZATION, TRANSFER TO
NURSING
HOME, AND HOSPITALIZATION, AND UNNECESSARY DEATH FIRSTHAND.
SEEING THIS, I BUILT A SIX PERSON FACILITY IN CALIFORNIA
THAT IS
CARE
IDEALLY SUITED AND READY FOR TESTING AS AN INTEGRATED ESRD
FACILITY.
I HAVE NOT BEEN ABLE TO GET IT CERTIFIED BECAUSE I WAS TOLD
THAT

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IT IS NOT WITHIN THE CURRENT CERTIFICATION CATEGORIES.
WE ARE NOT ASKING FOR GRANTS OR FUNDING.
WE ARE ONLY ASKING FOR A CHANGE IN REGULATION THAT WILL
PERMIT
US TO PROVIDE INTEGRATED CARE FOR THE ESRD PATIENTS.
THIS WILL ALLOW US TO BENEFIT OUR PATIENTS BY BREAKING THE
HELPING
CYCLE, RETURNING THEM TO A HEALTHIER QUALITY OF LIFE,
THEM TO LIFE WITHIN THE COMMUNITY, AND SAVING THE TAX PAYERS
OVER 30% OF THE ANNUAL COSTS FOR ESRD PATIENTS.

THANK YOU VERY MUCH FOR THIS LISTENING SESSION.

>> THANK YOU, MS. PUTMANN.

MR. PIPE?

AT
THE AGE OF SEVEN YEARS OLD AND HAVE FACED MANY COMPLICATIONS
THAT COME WITH THE DISEASE.
BECAUSE OF THAT I WAS DIAGNOSED AS DISABLED.
BUT SINCE THAT TIME I HAVE BEEN ELECTED AS A TRIBAL COUNCIL
MEMBER FOR MY TRIBES AS A FORT PECK SU IN THE SINAMORN
TRIBES IN
NORTHEAST MONTANA.
AND WITH THAT, I WOULD PROVIDE THE FOLLOWING TESTIMONY ON
BEHALF
OF MY TRIBE.
EDUCATION FOR OUR TRIBAL MEMBERS.
THE WELFARE REFORM MOVEMENT HAS MADE US AWARE OF THE FACT
THAT
AND 65
MANY OF OUR TRIBAL MEMBERS WHO ARE BETWEEN THE AGES OF 40
YEARS OF AGE ARE ILLITERATE.
IN MANY CASES THE ILLITERACY MAY BE LINKED TO MENTAL HEALTH
ISSUES, SUCH AS LEARNING DISABILITIES.

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HOWEVER, PSYCHOLOGICAL EVALUATIONS ARE VERY EXPENSIVE.
AND WHEN OUR CONSTITUENTS ARE DIAGNOSED BY QUALIFIED MENTAL
HEALTH PROFESSIONALS, WE ARE AT A LOSS OF WHAT TO DO WITH
THEM.
THESE INDIVIDUALS ARE HARD TO SERVE CLIENTS AND HAVE
SURFACED

DURING THE WELFARE REFORM MOVEMENT.

AN

IF THEY ARE CONSIDERED EMPLOYABLE, WHERE COULD WE PUT SUCH
INDIVIDUAL TO APPLY FOR EMPLOYMENT?

WHERE DO WE START THE EDUCATION PROCESS FOR 40 YEAR OLD
INDIVIDUALS WHO DO NOT HAVE THE QUALITY WORK ETHICS OR
QUALIFICATIONS TO MEET JOB REQUIREMENTS?

GRADE

FUNDING TO BEGIN EDUCATION PROGRAMS FOR INDIVIDUALS WHO ARE
MIDDLE AGED OR OLDER ARE NEEDED FOR INDIAN RESERVATION.
MANY OF OUR TRIBAL MEMBERS HAVE DROPPED OUT OF SCHOOL. AND
THOSE WHO HAVE FINISHED MAY HAVE BEEN PASSED FROM GRADE TO
THROUGH SOCIAL PROMOTION.

THE STUDENT WAS PASSED IN ORDER TO KEEP UP WITH HIS OR HER
STUDENT OF THEIR AGE.

WITH

THE FORT PECK INDIAN RESERVATION HAS MANY TRIBAL MEMBERS
DISABILITIES WHO ARE HOPING TO ENTER INTO THE COMMUNITY WORK
FORCE.

COMMUNITY

ON OUR RESERVATIONS WE HEAR ABOUT SHELTERED WORKSHOPS,
REHABILITATION PROGRAMS, INDEPENDENT LIVING CENTERS.
BUT WE DO NOT HAVE ACCESS TO THEM.

SHELTERED

FUNDING AND THE LACK OF TECHNICAL ASSISTANCE TO BUILD

INDEPENDENT

WORKSHOPS, COMMUNITY REHABILITATION PROGRAMS, AND
LIVING CENTERS ARE SCARCE ON OUR RESERVATION.

AGENCIES THAT PROVIDE THESE SERVICES DO SO TO THE GENERAL

POPULATION, BUT THE SERVICES DO NOT EXTEND TO THE INDIAN RESERVATION.

THE SERVICES ARE AVAILABLE TO THE MAJORITY OF THE STATE'S POPULATION.

MONTANA HAS A LARGE, HAS A HUGE BASE ON THE SEVEN INDIAN RESERVATIONS, AND IS A HIGHLY ISOLATED AREA, COMPARED TO THE REST OF THE STATE'S POPULATION.

AROUND THE FORT PECK INDIAN RESERVATION'S UNEMPLOYMENT HOVERS 65%.

MEMBERS AND SOME OF THIS RESULTS FROM POVERTY, UNEDUCATED TRIBAL WHO LACK WORK ETHICS AND JOB SKILLS.

DUE CHEMICAL DEPENDENCY DEVELOPS DUE TO THE LACK OF SELF-ESTEEM, TO THE JOBLESSNESS, AND A LACK OF HOPE FOR THEIR FUTURE.

THE FORT PECK TRIBES NEED FEDERAL AND STATE ASSISTANCE FOR ECONOMIC DEVELOPMENT SO OUR PEOPLE CAN HAVE A FUTURE TO LOOK FORWARD TO.

TECHNICAL ASSISTANCE AND FUNDING ARE PRIORITIES WE NEED TO DEVELOP OUR RESERVATIONS INTO PRODUCTIVE COMMUNITIES.

THANK YOU.

>> THANK YOU, MR. PIPE.

MS. ANTOINE?

PLEASE.

>> GOOD AFTERNOON.

TRIBE MY NAME IS ALFRETТА ANTOINE, A MEMBER OF THE SOLID RIVER OF ARIZONA.

BE I AM PROFOUNDLY DEAF, AND I KNOW FIRSTHAND WHAT IT'S LIKE TO
DISABLED.
INDIAN TODAY I AM HERE TO SPEAK IN BEHALF OF MY PEOPLE AND ALL
TRIBES ACROSS THE UNITED STATES.
THE NEEDS OF OUR DISABLED AND ELDERS ARE GREAT.
MAJOR CONCERNS ARE HOUSING, HEALTH CARE, TRANSPORTATION, AND
EDUCATION.
WITH THE BARRIERS ARE THAT TRIBES HAVE NOT HAD ACCESS TO FUNDING
PROVIDED BY THE STATE OR FEDERAL GOVERNMENT FOR COMPLIANCE
ADA.
FUNDING, FEDERAL AGENCIES WORK WITH STATES ON STATE PLANS AND
INCLUDE HOWEVER, ARE NOT REQUIRED -- STATES ARE NOT REQUIRED TO
TRIBES IN THE PLANNING.
STATE AND FEDERAL AGENCIES NEED TO REACH OUT TO TRIBES AND
INCLUDE THEM IN PLANNING.
OFTEN TRIBAL DATA IS USED TO JUSTIFY NEED WHEN APPLYING FOR
FUNDING.
AVAILABLE BUT THERE ARE NO PROVISIONS TO ASSURE WHEN FUNDS ARE
AND WHAT TRIBES, AND WHAT TRIBES RECEIVES FUNDING.
WE NEED TO ACCESS SERVICES AND DOLLARS TO ASSIST WITH
COMMUNITY-BASED SERVICES.
NATIVE AMERICAN TRIBES ARE EXEMPTED FROM THE AMERICANS WITH
DISABILITIES ACT, THEREFORE, WE FEEL THAT WE ARE BEING
DISCRIMINATED AGAINST.

SO
AND

WE NEED THE DOLLARS, THE TECHNICAL ASSISTANCE, AND SERVICES
THAT OUR DISABLED AND ELDERS CAN BEGIN TO LIVE PRODUCTIVE

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FRUITFUL LIVES.

THESE ARE THE GREATEST BARRIERS THAT INDIAN TRIBES ARE FACED
WITH.

THOUGHT

I RESPECTFULLY URGE THAT YOU GIVE MY TESTIMONY A LOT OF
AND CONSIDERATION.

SO
CAN

I ALSO URGE YOU TO BRING DOWN THESE BARRIERS THAT I SPOKE OF
THAT THOSE OF US WHO ARE PHYSICALLY AND MENTALLY CHALLENGED
BECOME A PART OF MAINSTREAM AMERICA.

THANK YOU.

>> THANK YOU VERY MUCH, MA'AM.

MS. ROTH, BEFORE WE GO TO YOU, I APOLOGIZE, LET ME THANK THE
FIRST PANEL FOR THEIR EXCELLENT TESTIMONY.

PROVIDING

AND LET ME INVITE THE NEXT GROUP OF FOUR THAT WILL BE
THEIR TESTIMONY TO PLEASE COME TO THE FRONT TABLE.

EXCUSE ME.

MS. ROTH?

>> GOOD AFTERNOON, EVERYBODY.

MY NAME IS MARCIE ROTH.

AND I'M THE DIRECTOR OF ADVOCACY AND PUBLIC POLICY FOR THE
NATIONAL COUNCIL ON INDEPENDENT LIVING.

CROSS

THE NATIONAL COUNCIL ON INDEPENDENT LIVING IS THE LARGEST

PEOPLE
DISABILITY ORGANIZATION IN THE COUNTRY, RUN BY AND FOR
WITH DISABILITIES.
I ACTUALLY HAD A PREPARED SPEECH, BUT I RIPPED IT UP.
I WOULD MUCH RATHER JUST SPEAK FROM MY HEART.
AS I SIT HERE LOOKING AT YOU ALL UP THERE, SOME OF YOU MY

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THE
FRIENDS, MOST OF YOU PEOPLE I KNOW, MANY OF YOU PEOPLE WHO I
HAVE NOT HAD AN OPPORTUNITY TO WORK WITH, BUT YOU ALL ARE
GATEWAY BETWEEN THE PEOPLE SITTING DOWN HERE AND REAL LIVES,
REAL CHOICES, REAL FUTURES FOR PEOPLE WITH DISABILITIES.
WE ALL COME TO YOU -- I DON'T KNOW HOW MANY OF YOU FOLLOWED
IN
THE EMAILS WHAT WAS GOING ON -- DID YOU GET YOUR TWO
MINUTES;
DID
DID YOU GET YOUR THREE MINUTES; DID YOU GET ASKED TO COME;
YOU GET A LITTLE BIT OF MONEY TO GET HERE?
THIS IS THE FIRST TIME WE'VE HAD THE OPPORTUNITY TO SIT
BEFORE
YOU ALL AND TO TELL YOU HOW IMPORTANT COMMUNITY LIVING IS TO
MILLIONS AND MILLIONS OF PEOPLE WHO ARE NOT GETTING THAT
THAT
OPPORTUNITY, WHO ARE NOT GETTING TO PARTAKE OF THE BOUNTY
THE REST OF THIS COUNTRY GETS TO PARTAKE OF.
AND I SIT HERE LISTENING TO OTHER PEOPLE SPEAKING
AND THE SORT OF SCRAPPING THAT'S GOING ON OVER, PICK MY
PROGRAM!
ELSESES ' INVEST IN MY PROGRAM! MY PROGRAM IS BETTER THAN ANYBODY

MOST

PROGRAMS BECAUSE MY PROGRAM SERVES THE PEOPLE I CARE THE

ABOUT!

THIS HAS GOT TO STOP.

TIME IS BEYOND US.

WE CAN NO LONGER DO THIS.

ELSE

THE BOTTOM LINE IS, PEOPLE HAVE A RIGHT TO WHAT EVERYBODY

ALREADY HAS.

THEY HAVE A RIGHT TO GET INVOLVED IN, TO BE PART OF, TO LIVE

REAL LIVES IN OUR COMMUNITIES.

SURE

IT'S OUR JOB, IT'S YOUR JOB, IT'S EVERYBODY'S JOB TO MAKE

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IT.

THAT WE GET FROM HERE TO THERE.

AND FRANKLY, I'M SICK AND TIRED OF ALL OF US TALKING ABOUT

OUR

PEOPLE ARE DYING IN OUR NURSING HOMES, PEOPLE ARE DYING IN

COMMUNITIES.

ENOUGH IS ENOUGH.

WE HAVE GOT TO GET TO WORK.

AND WE HAVE GOT TO MAKE IT POSSIBLE FOR PEOPLE TO ENJOY THE

CIVIL RIGHTS THAT ARE THEIRS, THAT ARE OURS.

LIVING

NOW, I WILL TAKE A MOMENT AND TALK ABOUT OUR INDEPENDENT

REAL

CENTERS BECAUSE AS I LISTEN TO EVERYBODY TALKING, IT WAS

MOST

CLEAR TO ME THAT THE INDEPENDENT LIVING CENTERS ARE DOING

OF WHAT PEOPLE ARE ASKING FOR MORE OF.

I'VE HEARD MANY PEOPLE SAYING, IF THERE WAS MORE MONEY FOR
INDEPENDENT LIVING CENTERS.

IN

WELL, INDEPENDENT LIVING CENTERS ARE RUN BY AND FOR PEOPLE
OUR COMMUNITIES.

DO YOU KNOW THAT IN 1999, THE LAST YEAR THAT WE HAVE FIGURES
FOR, OUR INDEPENDENT LIVING CENTERS GOT 2300 PEOPLE OUT OF
NURSING HOMES, AND THEY KEPT ALMOST 15,000 PEOPLE FROM BEING
FORCED INTO NURSING HOMES?

AND DO YOU KNOW THAT THEY DID IT FOR \$643.00 PER PERSON IN
FEDERAL DOLLAR?

\$643.00 PER PERSON TO KEEP SOMEBODY OUT OF A NURSING HOME.

IT'S A PRETTY BIG BANG FOR THE BUCK.

AND YOU KNOW WHAT?

THE

WE DID NOT GET ONE PENNY MORE IN THIS YEAR'S BUDGET TO SERVE

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COMMUNITY

PEOPLE OF THIS COUNTRY AS WE MAKE OUR COMMITMENT TO

LIVING, AS WE MAKE OUR COMMITMENT TO ALL OF THE THINGS THAT

WE'RE TALKING ABOUT, NOT ONE ADDITIONAL PENNY HAS BEEN

CENTERS.

ALLOCATED, HAS BEEN PROPOSED, FOR INDEPENDENT LIVING

SO OKAY, I'M GOING JUMPING INTO THE MIX.

I'M GOING TO SCRAP FOR THE BUCKS TOO.

IT IS MY > MS. ODADA?

>> HELLO.

I'M DR. AL ODADA FROM HOWARD UNIVERSITY RESEARCH

AND TRAINING CENTER.

I'M TRAINED IN REHABILITATION AT THE MASTER'S LEVEL AND IN
COMMUNITY HEALTH AND REHABILITATION AT THE DOCTORED LEVEL.
I HAVE BEEN A STUDENT FOR THE LAST THIRTY YEARS OF MY LIFE.
AND THAT'S WHY I'VE SEEN STUDENTS WITH DISABILITY, WITHOUT
DISABILITY, AND ALSO STUDENTS WHO HAVE COME TO THE UNITED
STATES
LOOKING FOR A BETTER EDUCATIONAL OPPORTUNITY.
AND THESE STUDENTS ALSO HAD DISABILITIES, DECLARED OR NOT.
BUT I HAVE ALSO SEEN, DURING MY STUDIES AT THE UNIVERSITY OF
ILLINOIS, HOW DISABILITY IS ONE OF THE PRIORITIES THERE.
AND ALSO MY STUDIES AT LOUISIANA STATE UNIVERSITY, AND
SOUTHERN
UNIVERSITY, A HISTORICALLY BLACK COLLEGE AND UNIVERSITY IN
LOUISIANA, HOW DISABILITY, HOW REHABILITATION ISSUES HAVE
TAKEN
A BACK-BURNER.
AND THAT IS WHY I'M HERE TODAY TO TALK ON BEHALF OF
STUDENTS,
NOT OFFICIALLY BUT JUST FROM MY HEART.
I HAVE SEEN THAT STUDENTS, WHEN THEY COME IN, THEY FACE
181
TREMENDOUS BARRIERS IN ASSISTIVE TECHNOLOGY, IN EVEN GRADING
PAPERS.
IN THE UNIVERSITY OF ILLINOIS, A PROFESSOR IN ONE OF THE
DEPARTMENTS HAD TO GO THROUGH A WHOLE PROCESS, GRADUATE
COUNSEL
BECAUSE
PROCESS, BECAUSE THE GRADING SYSTEM WAS DISCRIMINATORY
THIS STUDENT OF HIS WAS IN A WHEELCHAIR, AND HE FELT IT WAS
DISCRIMINATORY.

ALSO STUDENTS DON'T HAVE TRANSPORTATION.

I'M NOT TALKING ABOUT THE CITY TRANSPORTATIONS.

I'M TALKING ABOUT THE TRANSPORTATIONS THAT UNIVERSITIES RUN
WITHIN THE CAMPUS.

AM, I
AND WHEN WE TALK ABOUT STUDENTS OF FOREIGN ORIGINS LIKE I
STILL AM AN INDIAN CITIZEN.

I HAVE SEVERAL FRIENDS WHO HAVE DISABILITIES FROM OTHER
COUNTRIES WHO ARE NOT ELIGIBLE FOR VR SERVICES.

DOING
IF THEY ARE NOT ELIGIBLE FOR VR SERVICES, I THINK WE'RE

THESE
THE ENTIRE STUDENT POPULATION BY A DISSERVICE BY ADMITTING

STUDENTS IN THE UNIVERSITIES BUT NOT PROVIDING THEM WITH THE
REQUIRED SERVICE TO ATTAIN THEIR ACADEMIC GOALS.

WHERE
RSA AND NIDRR, THEY ARE DOING A LOT IN THIS REGARD. BUT

IS THAT FOCUS?

WHERE IS THAT EMPHASIS?

WHERE IS THAT MANDATE TO ACTUALLY MAKE UNIVERSITIES
PROVIDE THOSE BASIC SERVICES TO ALL STUDENTS, NOT ONLY TO
STUDENTS OF AMERICAN ORIGIN BUT OTHER STUDENTS TOO.

UNIVERSITIES
BECAUSE IF WE TALK ABOUT LSU -- AND A LOT OF THESE

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THAT HAVE ENGINEERING DEPARTMENTS, COMMUNITY COMPUTER SCIENCE

IS
DEPARTMENTS, IF THE FOREIGN STUDENTS LEAVE, THE DEPARTMENT

GOING TO CLOSE.

AT LSU, IF THE INDIAN STUDENTS FROM THE DEPARTMENT OF
ENGINEERING LEAVE, THE DEPARTMENT IS GOING TO BE HAVING TWO

STUDENTS PROBABLY.

AND THAT IS WHY, SINCE WE HAVE THIS TREMENDOUS EMPHASIS IN ATTRACTING FOREIGN STUDENTS, I THINK IT BECOMES ONE OF THE NECESSITIES, THAT THESE STUDENTS BE PROVIDED WITH SERVICES. THAT IS WHY I ENCOURAGE, I URGE ALL OF YOU, ESPECIALLY THE DEPARTMENT OF EDUCATION AND MAYBE THE DEPARTMENT OF LABOR,

TO

GIVE THE STUDENTS THE OPPORTUNITY TO SUCCEED.

AND ALSO WE HAVE THE REHAB STUDENTS AT OUR UNIVERSITIES THAT HAVE THE RSA GRANTS.

THEY ARE FUNDED.

BUT WHEN THEY GO TO THE STATE REHAB AGENCIES, THEY ARE NOT HIRED.

A LOT OF THEM ARE NOT HIRED.

ONE OF THE STATES THAT I'M FROM HAS A JOB FREEZE RIGHT NOW.

AND THEY'RE NOT HIRING ANYBODY.

AND THE STUDENTS ARE SUPPOSED TO PAY BACK.

SO WHAT ARE WE SUPPOSED TO DO TO ATTRACT MORE STUDENTS, KEEP THEM IN REHAB, AND NOT HAVE THEM GO BACK TO THE PRIVATE AGENCIES?

THAT WAY WE DO A DISSERVICE TO THE REHAB SERVICES ADMINISTRATION

AND TO THE TAXPAYER'S DOLLARS.

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IS IT TO POSSIBLE FOR US TO DO ANYTHING TO HELP THE STUDENTS WITH DISABILITIES, THE FOREIGN STUDENTS WITH DISABILITIES,

AND

ALSO OUR REHAB STUDENTS WHO ARE THERE TO HELP PEOPLE WITH DISABILITIES?

THANK YOU.

>> THANK YOU, DR. DADA.

MR. ELLIS, WE GO TO YOU, PLEASE.

>> THANK YOU VERY MUCH.

I APPRECIATE THE OPPORTUNITY.

LIKE

I WOULD LIKE TO PUT MY STATEMENT IN A CONTEXT THAT I FEEL

PERHAPS YOU COULD RELATE TO, THOSE OF YOU ON THE PANEL.

FIFTEEN YEARS AGO I WAS MARRIED.

I HAD A SIX FIGURE INCOME.

IN

I OWNED THREE HOMES, DROVE GERMAN CARS, VACATIONED IN EUROPE

THE ISLANDS.

I BASICALLY WAS WHAT I GUESS YOU MIGHT CALL A BONA FIDE

REAGANOMICS QUISINART YUPPY.

I HAD IT ALL.

BUT I DEVELOPED A DISABILITY.

I WAS DIAGNOSED WITH MS.

I LOST MY WIFE.

I LOST MY JOB.

I LOST MY HOUSES.

I LOST THE CARS.

I LOST THE VACATIONS.

I LOST IT ALL.

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NO

RIGHT NOW I LIVE WITH SOCIAL SECURITY DISABILITY, VIRTUALLY

ASSETS, IN A 500 SQUARE FOOT APARTMENT IN AN ELDERLY HOUSING

PROJECT.

NOW, I AM VERY THANKFUL.

IF THAT SURPRISES YOU, THAT I COULD BE THANKFUL FOR LIVING

IN AN ELDERLY HOUSING COMPLEX WITH 500 SQUARE FEET AND NO MONEY, I

LOOK AROUND ME AND I SEE HOW MUCH BETTER OFF I AM THAN MY

BROTHERS AND MY SISTERS.

THE WOMAN BEHIND ME THAT SPOKE EARLIER, FATIMA MILLER, SHE

HAS NO HOME.

AND I SEE SO MANY PEOPLE WITH DISABILITIES THAT EITHER HAVE

NO HOME OR THEY'RE HOUSED IN INSTITUTIONS.

AND MY FEAR IS, FOR MYSELF, AS MY DISABILITY PROGRESSES, I

WILL LOSE WHAT LITTLE I HAVE.

BECAUSE OF A LACK OF ATTENDED CARE IN THE HOME AND VARIOUS

DIFFERENT PROVISIONS THAT MI KASA COULD PROVIDE, ADHERENCE

TO THE OLMSTEAD PROVISION, I DON'T WANT TO LOSE THAT.

AND I WANT TO SEE THE PEOPLE WHO ARE IN THE INSTITUTIONS, IF

THEIR THEY CAN BE MOVED OUT, TO HAVE THEIR INDEPENDENCE, TO HAVE

OWN HOME, TO HAVE SOMEWHERE TO LIVE.

HAVE THAT'S WHY I'M THANKFUL FOR WHAT I'VE GOT BECAUSE I STILL

MORE TO LOSE.

THANK YOU VERY MUCH FOR THE OPPORTUNITY TO SPEAK.

I APPRECIATE IT.

>> THANK YOU VERY MUCH, MR. ELLIS.

AND THANK YOU TO THE PANEL.

IF I MIGHT ASK THE NEXT GROUP THAT WILL BE PROVIDING
TESTIMONY
TO COME AND PLEASE MOVE TO THE FRONT.
LET ME ALSO ASK THOSE OF YOU WHO WILL BE PRESENTING
TESTIMONY
LATER IN THIS SESSION HOLDING PINK CARDS, THE PINK GROUP, IF
YOU
WOULD ASSEMBLE IN THE BACK, PLEASE.
MS. SAYNOR, CAN WE TURN TO YOU, PLEASE?
>> YES.
MY NAME IS JANET SAYNOR.
I AM HERE TODAY AS AN OLDER PERSON, A FORMER CARE GIVER, AND
AS
A PROFESSIONAL IN THE FIELD OF AGING, PRIMARILY AS THE
FORMER
COMMISSIONER ON AGING FOR THE CITY OF NEW YORK.
I APPRECIATE THIS OPPORTUNITY TO TESTIFY ON THE PRESIDENT'S
NEW
FREEDOM INITIATIVE, AND COMMEND THE PRESIDENT FOR HIS
COMMITMENT
TO IMPLEMENT THE ADA AND ASSURE THAT ALL AMERICANS OF ALL
AGES
HAVE THE OPPORTUNITY TO HAVE FULL ACCESS TO COMMUNITY LIFE
AND
SERVICES.
DID YOU KNOW THAT OF THE 54 MILLION PEOPLE WITH
DISABILITIES, 17
MILLION, OR 33%, ARE OVER THE AGE OF 65, AND THAT NEARLY
HALF,
47%, ARE OVER THE AGE OF 55?
YES, THIS IS THE AGING POPULATION, A RAPIDLY GROWING ONE.
AND IF YOU ARE NOT THERE YET, YOU'RE BOUND TO REACH IT. AT
LEAST I HOPE SO.

THIS HOWEVER, NOT ONLY DO I WANT TO ADDRESS THE UNMET NEEDS OF
AND RAPIDLY GROWING AGING PROCESS, I ALSO HOPE WE CAN STRENGTHEN
HELP THEM UTILIZE COMMUNITY-BASED SERVICES.

BUT I ALSO WANT TO RECOGNIZE AND ADDRESS THE NEEDS OF THE

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GROWING NUMBER OF FAMILY CARE GIVERS AND OTHER INFORMAL CARE
GIVERS IN OUR SOCIETY.

THEY ARE OFTEN THE FORGOTTEN ONES.

THIS BUT THEY ARE THE MAJOR PROVIDERS OF CARE TO OLDER PEOPLE IN
COUNTRY.

GET OVER 90% OF DISABLED OLDER PEOPLE LIVING IN THE COMMUNITY

MOST OF THEIR EVERYDAY CARE FROM FAMILY CARE GIVERS.

CARE THEY ACTUALLY MAKE UP THE LARGEST COMPONENT OF OUR NATION'S

GIVER WORK FORCE AND WILL GO TO GREAT LENGTHS TO KEEP THEIR
LOVED ONE AT HOME.

BUT THEY DO SO AT GREAT COST.

TO THE PHYSICAL, EMOTIONAL, FINANCIAL DEMANDS OF PROVIDING CARE

A DISABLED LOVE ONE, SUCH AS A SPOUSE WHO HAS ALZHEIMER'S
DISEASE, CAN BE OVERWHELMING.

ROLE MANY FAMILIES EVENTUALLY BURN OUT FROM THIS TOLL THAT THIS

TAKES ON THEIR PERSONAL AND PROFESSIONAL LIVES.

OFTEN THE BURDEN AND BREAK DOWN OF THE FAMILY SUPPORT SYSTEM IS

HOME. THE KEY REASON WHY AN OLDER PERSON IS PLACED IN A NURSING
SUPPORT, I BELIEVE THAT THROUGH THE PROVISION OF MODEST HELP AND
AND SUCH AS RESPITE CARE, SUPPORT GROUPS, TRAINING, EDUCATION,
HELP IN ACCESSING EXISTING COMMUNITY SERVICES ON HOW TO GET
THROUGH THE BUREAUCRATIC SERVICES, THE GOVERNMENT CAN
SIGNIFICANTLY BOLSTER OUR NATION'S INFORMAL SUPPORT SYSTEM.
IN MY CURRENT ROLE AS SPECIAL CONSULTANT TO THE BROOKDALE
FOUNDATION, I HAVE SEEN FIRSTHAND, ACROSS THE NATION, THE
TREMENDOUS IMPACT SUCH SUPPORT CAN HAVE ON THE ABILITY OF

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FAMILIES TO CONTINUE THEIR CARE GIVING EFFORTS.
FOR THE FOUNDATION HAS FUNDED OVER 230 PROGRAMS OF RESPITE
PROGRAM ALZHEIMER FAMILY CARE GIVERS ACROSS THE COUNTRY, AND ANOTHER
FUNDING DIMENSION FOR GRANDPARENTS RAISING GRANDCHILDREN, THE
AGO. KNOWN AS THE RELATIVES AS PARENTS PROGRAM, WHICH STARTED
IN WITH LITTLE SEED GRANTS OF \$10,000 A FEW YEARS -- SIX YEARS
THIS AND SUSTAINING THESE PROGRAMS IN THEIR COMMUNITIES.
DEVELOPING A PARTNERSHIP WITH FAMILY CARE GIVERS, WHICH
THE CONSTITUTE A HUGE PRIVATE RESOURCE IN THE COUNTRY, CAN SAVE
GOVERNMENT MONEY BECAUSE IT WILL HELP FAMILIES TO EXTEND THE
ONE AT LENGTH OF TIME THEY ARE ABLE TO HELP CARE FOR THEIR LOVED

MORE

HOME AND IN THE COMMUNITY, THUS LESSENING THE TIME SPENT IN

OF

EXPENSIVE FORMS OF CARE, SUCH AS NURSING HOMES AND OTHER OUT

HOME PLACEMENTS.

HELPING

THEREAFTER, IF THE FEDERAL GOVERNMENT IS SERIOUS ABOUT

DISABLED

PEOPLE WITH DISABILITIES REMAIN AT HOME AND IN THEIR
COMMUNITIES, IT MUST ADDRESS NOT JUST THE NEEDS OF THE

PERSON, AS IMPORTANT AS THAT IS, BUT ALSO THE NEEDS AND THE
UNMET NEEDS OF FAMILY CARE GIVERS.

GIVERS

AND THEREFORE, I URGE YOU TO MAKE SUPPORT FOR FAMILY CARE

AND THOSE THEY LOVE AND CARE FOR, A DUEL INTERGENERATIONAL
CENTERPIECE OF THE PRESIDENT'S NEW FREEDOM INITIATIVE.

THANK YOU VERY MUCH.

>> THANK YOU VERY MUCH, MS. SAYNOR.

WE'LL MOVE TO MR. STERLING NOW.

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MEDICAID

AND I'LL JUST SAY VERY QUICKLY, I MAY STEP OUT FOR JUST A
SECOND.

BUT I THINK I WILL LEAVE THE MODERATION IN THE VERY CAPABLE
HANDS OF KATHY RAMA FROM THE CENTER FOR MEDICARE AND

SERVICES FOR JUST A MOMENT OR TWO.

MR. SPERLING?

>> THANK YOU.

MY NAME IS ANDREW SPERLING.

I'M DEPUTY EXECUTIVE DIRECTOR FOR POLICY FOR THE NATIONAL

ALLIANCE FOR THE MENTALLY ILL.

PEOPLE NAMI IS THE NATION'S LARGEST ORGANIZATION, REPRESENTING
WITH SEVERE AND PERSISTENT MENTAL ILLNESS IN THEIR FAMILIES;
210,000 MEMBERS, 1200 AFFILIATES IN ALL 50 STATES.

EFFORT FROM NAMI'S PERSPECTIVE, WE FIRST WANT TO NOTE THAT THIS
OF OLMSTEAD AND THE NEW FREEDOM INITIATIVE IS SOMETHING WE
STRONGLY SUPPORT.

INVENTED WE ALSO WANT TO GO ON RECORD AND NOTE THAT WE REALLY
THIS POLICY NEARLY FOUR DECADES AGO WHEN WE BEGAN THE SOCIAL
EXPERIMENT CALLED DEINSTITUTIONALIZATION IN THIS COUNTRY.

MENTAL AND WE TOOK MORE THAN HALF A MILLION PEOPLE WITH SEVERE
THE ILLNESS THAT WERE IN STATE HOSPITALS AND INTEGRATED THEM IN
COMMUNITY.

AND FROM NAMI'S PERSPECTIVE, IT WAS A PROCESS THAT DIDN'T GO
PARTICULARLY WELL.

AND WE SEE THE RESULTS TODAY ALL ACROSS THIS COUNTRY.
WE HAVE MORE PEOPLE WITH SEVERE MENTAL ILLNESS IN JAILS THEN
WE

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ON DO IN HOSPITALS IN THIS COUNTRY.
IN MOST MAJOR CITIES, UPWARDS OF 40% TO 50% OF THE HOMELESS,
THE STREETS AND IN SHELTERS, ARE PEOPLE
THROUGH, SO WE WANT TO SORT OF GIVE A WARNING THAT WE'VE BEEN
OVER THE LAST FORTY YEARS, A PROCESS OF MOVING PEOPLE FROM

INSTITUTIONAL CARE INTO THE COMMUNITY.

AND QUITE FRANKLY, FROM NAMI'S PERSPECTIVE, IT HASN'T GONE TERRIBLY WELL.

COMMENTS

I WANT TO SUMMARIZE A FEW POINTS THAT NAMI MADE IN ITS THAT WERE SUBMITTED ON THE PRESIDENT'S EXECUTIVE ORDER.

FIRST, NAMI SUPPORTS REPEAL OF THE IMD EXCLUSION UNDER THE MEDICAID LAWS.

LIVES

IT WAS A FORM OF DISCRIMINATION BASED ON WHERE A PERSON RATHER THAN WHAT THEY NEED.

FLEXIBILITY

SECOND, WE WANT TO SEE GREATER INVESTMENT, GREATER

SUCH

FOR THE STATES TO INVEST IN EVIDENCE BASED BEST PRACTICES, AS A PROGRAM OF ASSERTIVE COMMUNITY TREATMENT.

ALL

ON THE ISSUE OF HOUSING, WHICH NAMI BELIEVES IS CENTRAL TO

AND

OF THIS, THAT ALL OF THESE OBJECTIVES WE HAVE ABOUT RECOVERY

INDEPENDENCE,

GREATER INTEGRATION INTO THE COMMUNITY, AND MORE

HOUSING.

ARE ALL BUILT ON ACCESS TO DECENT, SAFE, AND AFFORDABLE

BE

SO OF MY COLLEAGUES, BOTH TO MY IMMEDIATE RIGHT, THEY WILL

TALKING ABOUT THE ISSUE OF HOUSING IN GREATER DETAIL.

PROGRAMS,

BUT NAMI BELIEVES THAT WE NEED ACCESS TO MAINSTREAM

MAINSTREAM HUD PROGRAMS FOR PEOPLE WITH DISABILITIES.

WE NEED FOCUS ON RENTAL HOUSING SO THAT PEOPLE WITH SSI, FOR

WHOM HOME OWNERSHIP SIMPLY WILL NOT WORK, WILL GET ACCESS TO HOUSING.

TO
AND WE BELIEVE THAT HUD'S ACCESS HOUSING 2000 PROGRAM NEEDS
THAT A
BE SIGNIFICANTLY REVISED, IF NOT REPEALED ALTOGETHER, SO
MORE WORKABLE PROGRAM CAN BE DEVELOPED.

HAVE
THE ACCESS HOUSING 2000 PROGRAM, JUST FOR THE RECORD, WOULD
BROUGHT
ACTUALLY -- THE TWO PLAINTIFFS IN GEORGIA WHO ORIGINALLY
THE OLMSTEAD CASE WOULD HAVE BEEN INELIGIBLE UNDER THE
GUIDELINES THAT HUD DREW UP.

ONE AND TWO, THEY ACTUALLY TOOK RESOURCES FROM ANOTHER VERY
MODEST, SMALL PROGRAM AT HUD THAT WAS SERVING PEOPLE WITH
DISABILITIES TO FUND THIS.

THAT
NAMI BELIEVES THIS IS NO WAY TO MOVE FORWARD OF ENSURING
THERE ARE RESOURCES AVAILABLE AS STATES MOVE FORWARD IN
IMPLEMENTING OLMSTEAD.

INCENTIVES
FOURTH, WE WANT TO SEE THE TICKET TO WORK AND WORK
IMPROVEMENT ACT PROGRAM FIXED, THE TICKET PROGRAM.

WITH
THERE ARE SOME SIGNIFICANT PROBLEMS FORM NAMI'S PERSPECTIVE
THE REGULATIONS, TO ENSURE THAT PEOPLE WITH SEVERE MENTAL
AND
ILLNESS CAN GET A TICKET AND CAN GET THAT CONSUMER CHOICE
GET THE OPPORTUNITY TO GO OUT IN THE WORK FORCE.

WORK
AND FINALLY, WITH THE ISSUE OF CRIMINALIZATION, WE WANT TO
WITH THE DEPARTMENT OF JUSTICE TO GET GREATER RESOURCES TO
COMMUNITIES TO DEAL WITH THE OVERWHELMING BURDEN THAT'S ON
THE

CRIMINAL JUSTICE SYSTEM FOR PEOPLE WITH UNTREATED SEVERE AND
PERSISTENT MENTAL ILLNESS.

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AUTHORED,
THE MENTAL HEALTH COURTS PROGRAM THAT SENATOR DEWINE
THERE ARE A LOT OF OTHER STRATEGIES.
BUT THE JUSTICE DEPARTMENT NEEDS TO TAKE A LEADERSHIP ROLE
IN
HELPING STATES AND COMMUNITIES COPE WITH THIS BURDEN.
THANK YOU.
>> MR. SPERLING, THANK YOU VERY MUCH.
MS. GALBRAITH, WE MOVE TO YOU PLEASE.
>> THANK YOU.
ON BEHALF OF THE AMERICAN NETWORK OF COMMUNITY OPTIONS AND
RESOURCES, ANCOR, AND IT'S 700 PRIVATE PROVIDERS OF SUPPORTS
TO
OTHER
HIS
EXECUTIVE ORDER AND COMMITTING THE NATION TO A SYSTEM OF
COMMUNITY-BASED ALTERNATIVES FOR INDIVIDUALS WITH
DISABILITIES.
HIS COMMITMENT IS IN KEEPING WITH ANCOR'S BELIEF THAT PEOPLE
WITH MENTAL RETARDATION AND OTHER DISABILITIES HAVE THE
RIGHT TO
THAT
CHOOSE WHERE THEY LIVE AND WORK, THE SERVICES AND SUPPORTS
THEY RECEIVE, AND WITH WHOM THEY ASSOCIATE.
HOWEVER, UNTIL THIS NATION TRULY COMMITS TO COMMUNITY
ALTERNATIVES THROUGH LAW, REGULATION, AND FUNDING, AND

MORE DETERMINES HOW COMMUNITY SUPPORTS NEED TO WORK, THAT IS, BE
ACCOUNTABLE IN FLEXIBLE, BE DETERMINED BY THE INDIVIDUAL, AND BE
THE TERMS OF IMPORTANT OUTCOMES, IT WILL BE DIFFICULT TO REACH
THE GOAL OF A SYSTEM OF COMMUNITY-BASED SUPPORTS AND SERVICES.
AND THE FEDERAL, STATE, AND LOCAL GOVERNMENTS MUST RECOGNIZE
THEY THAT THE DELIVERY OF SUPPORTS HAVE EVOLVED OVER TIME, AND

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WILL CONTINUE TO EVOLVE, AND THAT FEDERAL, STATE, AND LOCAL
PUBLIC POLICY AND REGULATIONS MUST BE IN KEEPING WITH THESE
CHANGES.

PRESIDENT'S THE U.S. SUPREME COURT DECISION IN OLMSTEAD, AND THE
EXAMINE COMMITMENT, HOWEVER, WILL BE A HOLLOW VICTORY UNLESS WE
NATION'S THE FOUR OVERARCHING BARRIERS THAT ARE ESSENTIAL TO THE
INFRASTRUCTURE IN DETERMINING COMMUNITY ALTERNATIVES.
ONE IS A 40 YEAR OLD, OUTDATED, FEDERAL LONG-TERM SUPPORT
PROGRAM AND FINANCING MECHANISM, THAT IS MEDICAID, WITH ITS
PARTNERSHIP, A CURRENT FLAWS, PREDICATED ON A FEDERAL AND STATE
BASED STATUTORY INSTITUTIONAL BIAS, MAKING HOME AND COMMUNITY-
SERVICES AN OPTION, AND BUILT IN FLEXIBILITY WHICH LEADS TO
BETWEEN INCONSISTENT AND DISPARATE COMMUNITY SERVICES, NOT ONLY
STATES BUT WITHIN THE STATES.

AND THESE HAVE TO BE CHANGED IF WE ARE TO MEET THE
COMMITMENT TO

HOME AND COMMUNITY-BASED SUPPORTS.

IN TERMS OF RECOMMENDATIONS, I WOULD LIKE TO RECOMMEND THAT
THE

PRESIDENT CONVENE A WHITE HOUSE SUMMIT IN THE EARLY PART OF
2002

ON COMMUNITY AND LONG-TERM SERVICES AND TO IDENTIFY THE
NATION'S

CURRENT STATE OF PREPAREDNESS, TO MEET WHAT I THINK IS
PROBABLY

THE MOST IMPORTANT CHALLENGE FACING US IN THE 21ST CENTURY.

IN TERMS OF THE MEDICAID LAW, I WOULD URGE THE PRESIDENT TO
PROPOSE IN HIS 2003 BUDGET, AND CONGRESS ENACT, THE
ELIMINATION

OF THE HOME AND COMMUNITY-BASED WAIVER AS A WAIVER SERVICE
TO

MAKE IT A MANDATORY SERVICE, BARRING MAKING IT A MANDATORY
SERVICE, WHICH I KNOW IS SWIMMING UPSTREAM HERE, AT MINIMUM
TO

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MAKE IT AN OPTIONAL SERVICE.

HOWEVER, JUST LIKE WITH THE HCFA WAIVER, WE ARE CONCERNED
THAT

OPTIONAL SERVICES MAY MEAN THAT STATES WHO DETERMINE SERVICE
DELIVERY SYSTEMS IN THEIR STATE MAY MAKE OPTIONAL SERVICES

NOT

AVAILABLE.

IT IS NOT AN OPTIONAL SERVICE.

THIS IS A NECESSITY TO PEOPLE WITH DISABILITIES.

AND IN CLOSING, I WOULD LIKE TO RECOMMEND THAT CMS AND THE
DEPARTMENT OF JUSTICE ALSO MONITOR THE WAGE DISPARITY THAT

EXISTS IN STATES WHICH INFLUENCES ADVERSELY THE CAPACITY OF STATES TO PROVIDE HOME AND COMMUNITY-BASED SERVICES TO INDIVIDUALS.

AND ONE LAST COMMENT ON HOUSING THAT'S ESSENTIAL TO ALL OF THIS.

WE WOULD RECOMMEND THAT THE PRESIDENT COME FORWARD IN HIS BUDGET

INDIVIDUALS WITH \$50 MILLION FOR VOUCHERS, STRICTLY FOR THOSE

WHO HAVE BEEN ON WAITING LISTS FOR SOME TIME, AND 10,000 VOUCHERS FOR THOSE INDIVIDUALS DIRECTLY TO BE AT THE OLMSTEAD

ISSUE.

MY TIME IS WAY PAST.

THANK YOU.

>> THANK YOU MS. GALBRAITH.

WE MOVE NOW TO MS. PROWL.

>> YES.

THANK YOU FOR THE OPPORTUNITY TO SPEAK ON BEHALF OF THE NATIONAL

ASSOCIATION OF PROTECTION ADVOCACY SYSTEMS.

OUR MEMBERS ARE STATE -- EXIST IN EVERY STATE.

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THEY ARE FEDERALLY MANDATED TO PROVIDE FREE LEGAL SERVICES TO

PEOPLE WITH DISABILITIES, THE WHOLE RANGE OF DISABILITIES IN DIFFERENT PRIORITY AREAS.

MANY OF OUR MEMBERS, ACTUALLY IN EVERY STATE, HAVE BEEN VERY INVOLVED WITH OLMSTEAD PLANNING ISSUES, BECAUSE WE KNOW THAT THE

PLAN WILL BE USED BY THE STATES AS A DEFENSE TO FAILURE TO

COMPLY WITH THE ADA INTEGRATION MANDATE.

AND MANY OF OUR MEMBERS HAVE SUBMITTED COMMENTS ABOUT DEFICIENCIES WITH PLANS, BUT STATES HAVE GONE AHEAD AND SENT TO THE OFFICE OF CIVIL RIGHTS AS THE PLAN, THE COMPREHENSIVELY EFFECTIVELY WORKING PLAN FOR IMPLEMENTING OLMSTEAD.

AND OUR FIRST RECOMMENDATION IS TO ENSURE ADEQUATE FUNDING FOR THE HHS OFFICE OF CIVIL RIGHTS AND THE DEPARTMENT OF JUSTICE TO ENABLE THEM TO EFFECTIVELY INVESTIGATE ALL OLMSTEAD COMPLAINTS WITHIN CLEAR TIME FRAMES AND TO ENABLE THEM TO EFFECTIVELY REVIEW ALL OF THE OLMSTEAD PLANS THAT STATES ARE SUBMITTING AS A DEFENSE OR AS A COMPREHENSIVE, EFFECTIVELY WORKING PLAN FOR MOVING PEOPLE INTO APPROPRIATE INTEGRATED SETTINGS.

WHILE WE HAVE BEEN VERY HAPPY AT THE FEDERAL LEVEL, WITH A VERY GOOD COLLABORATION BETWEEN THE OFFICE OF CIVIL RIGHTS, AND CMS, AND COLLABORATION WITH THE DISABILITY COMMUNITY, WE HAVE HEARD FROM OUR MEMBERS THAT OCR REGIONAL OFFICES DO NOT HAVE THE STAFF OR RESOURCES TO EFFECTIVELY INVESTIGATE ALL OLMSTEAD COMPLAINTS RECEIVED.

AND THIS IS EXTREMELY FRUSTRATING TO PNA'S AND ADVOCATES WHO ARE STRUGGLING TO GET THE ATTENTION OF STATES WHO ARE FAILING TO

ADDRESS OLMSTEAD COMPLIANCE, OR ARE DOING SO AT A SNAIL'S
PACE
AND ISSUING PLANS THAT ARE FAR FROM COMPREHENSIVE.
JUST AS HHS' OLMSTEAD LETTERS AT THE FEDERAL LEVEL HAVE
PROVIDED
VITAL AUTHORITY, AND HAVE REALLY PROVIDED WHAT WE NEEDED TO
BACK
ADVOCATE'S COMMENTS TO STATES, THAT THEY MUST IMPLEMENT
OLMSTEAD, WE WOULD LIKE ADEQUATE FUNDING FOR OCR TO BE ABLE
TO
ISSUE CLEAR TIME FRAMES FOR OLMSTEAD COMPLIANCE REVIEWS AND
PLAN
REVIEWS, WHICH WOULD PROVIDE THE INCENTIVE THAT IS CURRENTLY
LACKING FOR STATE'S TO MAKE OLMSTEAD IMPLEMENTATION A
PRIORITY,
AND FOR STATES TO ENSURE THAT THEIR PLANS INDEED MEET THE
STRONG
RECOMMENDATIONS THAT WERE ISSUED BY OCR AND CMS IN THEIR
FIVE
MEDICAID DIRECTOR LETTERS.
WE ARE PARTICULARLY CONCERNED ABOUT PNA REPORTS THAT BECAUSE
OF
AN OVERLOAD AND LACK OF RESOURCES THAT NO EFFORT IS BEING
MADE
TO REVIEW PLANS THAT STATES HAVE ACTUALLY SUBMITTED.
AND THEY'RE, IN FACT, ONLY FOCUSING ON STATES THAT HAVE SAID
THEY'RE NOT GOING TO SUBMIT PLANS BECAUSE THEY THINK THEY
ALREADY COMPLY.
AND THIS IS VERY DISCOURAGING.
PNA'S, ALONG WITH MANY DISABILITY ADVOCATES, HAVE SUBMITTED
COPIOUS LETTERS TO GOVERNORS AND OTHERS AS TO WHY THESE
PLANS
DON'T ADDRESS HOUSING, TRANSPORTATION, VETERANS, DON'T HAVE
ADEQUATE ASSESSMENTS, DON'T PROVIDE INFORMED CHOICE, ALL OF
THE

KEY RECOMMENDATIONS THAT OCR SUBMITTED.

CURRENTLY AND YET WE KNOW THAT OCR DOES NOT HAVE THE RESOURCES

TO GO BEHIND AND ACTUALLY REVIEW THESE PLANS.

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AND WE WOULD ENCOURAGE HHS TO PROVIDE ADEQUATE FUNDING.

THANK YOU.

>> THANK YOU VERY MUCH FOR YOUR TESTIMONY.

ACTUALLY, THANK YOU TO ALL OF THE PANEL FOR YOUR EXCELLENT TESTIMONY.

AS I HAVE SAID BEFORE, I WOULD LIKE THE NEXT GROUP OF PEOPLE PROVIDING TESTIMONY TO PLEASE COME DOWN TO THE FRONT.

AND MS. LARSON, WE'LL GO TO YOU, PLEASE.

>> GOOD AFTERNOON, LADIES AND GENTLEMEN.

MY NAME IS DEBORAH LARSON.

AND I'M ON THE BOARD OF THE NATIONAL ASSOCIATION ON ALCOHOL, DRUGS, AND DISABILITY.

I'M ALSO THE EXECUTIVE DIRECTOR OF THE GRANADA HOUSE FOR SUBSTANCE ABUSERS IN RECOVERY, AND WE'RE LOCATED IN AUSTIN, MASSACHUSETTS.

YEARS I WOULD LIKE TO TELL YOU ABOUT SOMETHING THAT HAPPENED TEN

AGO.

TREATMENT, TEN YEARS AGO A MAN CAME TO ME AND SAID, TAKE ME INTO

I'M READY TO GET SOBER.

AND HE WAS IN A WHEELCHAIR.

ACCESSIBLE. AND I COULDN'T TAKE HIM BECAUSE MY FACILITY WASN'T

SO I HAD TO TAKE HIM INTO OUTPATIENT EVEN THOUGH I KNEW HE
NEEDED INPATIENT.

LOCATED AND DESPITE, LADIES AND GENTLEMEN, THE FACT THAT WE WERE
GET ON A FEDERALLY FUNDED PUBLIC HEALTH HOSPITAL, WE COULDN'T
ACCESSIBLE FACILITIES.

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THIS GENTLEMAN'S NAME WAS PAUL WINLER.

PAUL WINLER DIED IN OUTPATIENT TREATMENT.

SEE I VOWED THAT I WOULD MAKE IT MY PERSONAL MISSION IN LIFE TO

ONLY THAT THAT DIDN'T HAPPEN AGAIN AND TO SEE THAT PEOPLE, NOT

TREATMENT IN THE STATE OF MASSACHUSETTS BUT IN THIS NATION, GOT

WHEN THEY NEEDED IT IF THEY WERE DISABLED.

DISABILITY LAST MAY I RECEIVED A VERY DISTURBING EMAIL FROM A

ADVOCATE.

I WOULD LIKE TO READ IT TO YOU.

TREATMENT IN IT'S REGARDING A PERSON, SHE WAS TRYING TO GET INTO

MARYLAND.

ABOUT "MY FRIEND WAS CLEAN AND SOBER FOR TEN YEARS AND RELAPSED

FOUR YEARS AGO.

HE IS A QUADRIPLAGIC AFTER BREAKING HIS NECK 28 YEARS AGO.

HIS HE WANTS RESIDENTIAL TREATMENT IN A 28 PROGRAM, BUT DUE TO

NEED FOR PERSONAL ASSISTANT SERVICES AND WHEELCHAIR

ACCESSIBILITY, HE HAS BEEN REFUSED BY EVERY REHAB HE HAS
APPROACHED IN OUR HOME STATE OF MARYLAND.

HEADS OF
ACCESSIBLE
WE HAVE CALLED, EMAILED, AND FAXED THE STATE AND COUNTY
ADDICTION SERVICES TO ASK THEM WHICH PROGRAMS PROVIDE
TREATMENT SERVICES AS REQUIRED BY LAW.
BUT NEITHER RESPONDED.

WANTS
ALCOHOLISM
I'M DOING MY BEST TO SUPPORT A WONDERFUL PERSON WHO SIMPLY
TO, WANTS THE OPPORTUNITY TO RECEIVE TREATMENT FOR
JUST LIKE ANY OTHER ALCOHOLIC.

I'M QUITE FEARFUL THAT HIS WILLINGNESS WILL FADE IF WE DON'T

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KILL
OF
HAD A
TO
FIND TREATMENT QUICKLY, OR WORST, THAT HIS BEHAVIOR WILL
HIM WHILE WE'RE TRYING TO GET HIM INTO TREATMENT, TREATMENT
THAT'S HE'S LEGALLY ENTITLED TO."
THIS PERSON FINALLY GOT INTO TREATMENT, BUT ONLY AFTER A LOT
PRESSURE WAS EXERTED NATIONALLY.
EIGHTEEN YEARS AGO A TREATMENT DIRECTOR TOOK A CHANCE ON A
TRAUMATICALLY BRAIN INJURED CLIENT WHO WALKED WITH A CANE,
SEVERE SPEECH IMPEDIMENT AND READ BASICALLY NOT AT ALL, DUE
HER TRAUMATIC BRAIN INJURY.
SHE WAS AN ALCOHOLIC.
SHE HAD A MORAL RIGHT AND A LEGAL RIGHT TO TREATMENT.
SHE GRADUATED FROM THAT PROGRAM.

I AM THAT CLIENT.

I AM EIGHTEEN YEARS SOBER.

AND I'M DIRECTOR OF THAT TREATMENT PROGRAM.

PROBLEMS,
FOR PEOPLE WITH DISABILITIES WHO HAVE SUBSTANCE ABUSE

WE BESEECH YOU, ENFORCE THE LAW.

THAT'S ALL WE ASK.

THANK YOU.

>> THANK YOU, MS. LARSON.

MS. O'HARA?

>> THANK YOU.

MY NAME IS ANN O'HARA.

I'M TESTIFYING TODAY ON BEHALF OF THE TECHNICAL ASSISTANCE

COLLABORATIVE, WHICH IS A NON-PROFIT ORGANIZATION ALSO IN

BOSTON, BUT ALSO FOR THE CONSORTIUM FOR CITIZENS WITH

199

DISABILITIES, AND SPECIFICALLY THEIR HOUSING TASK FORCE.

I AM HERE TODAY TO TALK TO YOU ABOUT THE ISSUE OF HOUSING.

SO OFTEN, COMMUNITY LIVING GETS FRAMED IN THE CONTEXT OF THE
DELIVERY OF SUPPORT SERVICES.

PLACE
BUT COMMUNITY LIVING REALLY FUNDAMENTALLY MEANS HAVING A

TO LIVE.

PLACE
IT MEANS HAVING A DECENT, A SAFE, AFFORDABLE, ACCESSIBLE

THAT'S
TO LIVE, A HOME, THAT YOU HAVE CHOSEN IN THE COMMUNITY

JUST EVERYONE ELSE'S'.

COMMUNITY
AND WITHOUT THAT, THE REST OF THIS DISCUSSION ABOUT

LIVING REALLY DOESN'T GET YOU VERY FAR.

THERE ARE TWO PROBLEMS WITH THE HOUSING ISSUE.

THE FIRST IS AN INCOME ISSUE.

AND PEOPLE WITH DISABILITIES ARE DISPROPORTIONATELY POOR.

THEY ARE AMONG THE POOREST PEOPLE IN THE UNITED STATES.

PEOPLE WITH SSI AND SSD BENEFITS CANNOT AFFORD HOUSING

WITHOUT

ASSISTANCE.

WE JUST COMPLETED A STUDY WHICH SHOWS THAT THE AVERAGE

PERSON

RECEIVING SSI IN THE UNITED STATES PAYS -- WOULD HAVE TO PAY

98%

OF THEIR MONTHLY BENEFIT TO RENT AN APARTMENT THAT IS

MODDESTLY

PRICED AT THE HUD FAIR MARKET RENT.

SO WE HAVE A REAL NEED FOR HOUSING ASSISTANCE FOR EVERYONE

WHO

IS ON SUPPLEMENTAL SECURITY INCOME OR DISABILITY BENEFITS.

THE SECOND ISSUE THAT'S COMPLETELY RELATED TO THAT IS THE

ISSUE

OF FEDERAL HOUSING PROGRAMS.

BECAUSE NO MATTER WHERE YOU LIVE, IF YOU LIVE IN BOSTON OR

YOU

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LIVE IN MASSACHUSETTS OR YOU LIVE IN FLORIDA, MOST OF THE

MONEY

THAT IS SPENT ON HOUSING COMES FROM THE FEDERAL GOVERNMENT.

AND PEOPLE WITH DISABILITIES RECEIVE LESS ASSISTANCE FROM

THE

FEDERAL GOVERNMENT THAN ANY GROUP RELATIVE TO THEIR NEED FOR

HOUSING ASSISTANCE.

WHO I LISTENED SO -- TO THE ELOQUENT TESTIMONY OF THE GENTLEMAN
TALKED ABOUT HIS 500-SQUARE-FOOT APARTMENT IN ELDERLY
HOUSING.
WE HAVE LOST 300,000 APARTMENTS IN ELDERLY BUILDINGS FOR
PEOPLE
WITH DISABILITIES BECAUSE WE NOW HAVE LAWS WHICH SAY THAT
PEOPLE
WITH DISABILITIES CAN'T MOVE INTO A LOT OF THESE ELDERLY
DEVELOPMENTS THAT THEY USED TO BE ABLE TO LIVE IN.
WE HAVEN'T REPLACED THAT HOUSING.
ALL WE HAVE IS ABOUT 50,000 SECTION 8 VOUCHERS, WHICH ARE
AND NOWHERE NEAR THE NUMBER OF UNITS THAT HAVE BEEN CONVERTED
ARE NO LONGER AVAILABLE.
I HAVE FIVE RECOMMENDATIONS THAT ARE RELEVANT TO THIS
DISCUSSION.
SPECIFIC THE FIRST IS THAT WE CAN'T RELY ON BOUTIQUE DISABILITY
PROGRAMS ANYMORE AT HUD TO MEET THIS NEED.
PEOPLE WITH DISABILITIES HAVE TO BENEFIT FROM EVERY SINGLE
PROGRAM THAT HUD PROVIDES.
PROGRAMS AND IN PARTICULAR, PROGRAMS THAT WE CALL MAIN STREAM
THAT TYPICALLY ARE ADMINISTERED BY STATE AND LOCAL HOUSING
OFFICIALS.
IN PARTICULAR THE HOME PROGRAM RARELY IS USED TO ADDRESS THE
HAS HOUSING NEEDS OF PEOPLE WITH DISABILITIES AND THAT PROGRAM
BEEN ALMOST \$2 BILLION A YEAR IN APPROPRIATIONS.

WE NEED TO MAKE SURE THAT PEOPLE WITH DISABILITIES AND THEIR
ADVOCATES ARE PART OF ALL OF THE HOUSING PLANNING THAT IS
NOW
REQUIRED AT THE STATE AND LOCAL LEVEL.
WE NEED TO CONTINUE TO TARGET SECTION 8 VOUCHERS FOR PEOPLE
WITH
DISABILITIES AND WE NEED TO MAKE SURE THAT WE DON'T
UNDERFUND
SOME VOUCHER PROGRAMS FOR PEOPLE WITH DISABILITIES SO THAT
WE
CAN FUND NEW ONES.
WE NEED NEW MONEY AND WE NEED TO KEEP EVERYTHING THAT WE
ALREADY
HAVE.
WE NEED TO MODERNIZE AND IMPROVE THE SECTION 811 PROGRAM,
WHICH
IS A DISABILITY SPECIFIC PROGRAM AT HUD.
UNFORTUNATELY, THERE HAS BEEN A LOT OF TINKERING THAT'S GONE
ON
WITH THIS PROGRAM OVER THE LAST THREE OR FOUR YEARS TRYING
TO
IMPROVE IT.
I BELIEVE THAT THAT TINKERING HAS REALLY JUST MADE THE
PROGRAM
MORE DIFFICULT TO USE, AND I REALLY BELIEVE IT NEEDS A
COMPLETE
REAUTHORIZATION.
AND THEN FINALLY, I DON'T WANT TO STOP WITHOUT MENTIONING
THE
ISSUE OF ACCESSIBLE HOUSING.
ACCESSIBLE HOUSING IS A CRITICAL PROBLEM.
THE FACT THAT WE DON'T HAVE ACCESS TO THESE ELDERLY
DEVELOPMENTS
ANYMORE MEANS THERE IS LESS ACCESSIBLE HOUSING.
THERE ARE A LOT OF WAYS THAT HUD COULD WORK WITH LOCAL

GOVERNMENTS TO EXPAND ACCESS TO ACCESSIBLE HOUSING USING
VOUCHERS AND OTHER RESOURCES.

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THANK YOU VERY MUCH.

>> THANK YOU, MS. O'HARA.

MS. BERMUDEZ?

>> ALOHA Y'ALL.

THE
BEFORE I BEGIN, I WOULD LIKE TO BRING HONOR AND RESPECT TO
ELDERS WHO PRECEDED ME AND THOSE WHO WILL FOLLOW ME.

MY NAME IS KINIKE BERMUDEZ.

I AM A PERSON WITH DIABETES, ARTHRITIS, CARPAL TUNNEL.

AND 10 YEARS AGO WAS DIAGNOSED WITH BIPOLAR DISORDER.

I HAVE EXPERIENCED HOMELESSNESS IN THE STATE OF TEXAS.

NINE.
I GAVE UP CUSTODY OF MY CHILDREN WHEN THEY WERE SEVEN AND

I'M A SECOND-GENERATION AMERICAN, BORN IN BROOKLYN.

UNTIL I WAS SIX, I THOUGHT I WAS PUERTO RICAN.

I FOUND OUT FROM MY MOM THAT I'M FILIPINO/HAWAIIAN/CHINESE.

AN
I'M HERE TODAY BECAUSE THE NEW FREEDOM INITIATIVE ADDRESSES

ISSUE FOR A POPULATION THAT'S GROWING AND GROWING.

AND THAT IS THE ASIAN AMERICAN, PACIFIC ISLANDER POPULATION.

I'M A FOUNDING MEMBER OF THE NATIONAL ASIAN AMERICAN PACIFIC

ISLAND MENTAL HEALTH ASSOCIATION, OTHERWISE KNOWN AS NAPIMA.

I ALSO A MEMBER OF THE NATIONAL PEOPLE OF COLOR CONSUMER

SURVIVOR.

I'M ALSO A MEMBER OF THE CHAPTER DEVELOPMENT OF THE NATIONAL

DEPRESSIVE AND MANIC DEPRESSIVE ASSOCIATION.

THE FREEDOM THAT WE TAKE SOMETIMES FOR GRANTED AS A SECOND
GENERATION AMERICAN IS SOMETHING THAT THESE PEOPLE FROM THE
PACIFIC, FROM ASIA ARE STRIVING TO ACHIEVE AND THAT'S
FREEDOM,

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BUT THE ABILITY TO GET ACCESS, THE MAJOR BARRIER IS
LANGUAGE.

I AM PROUD TO SAY THAT I ALSO SERVED ON THE SURGEON
GENERAL'S

REPORT ON MENTAL -- ON RACISM -- CULTURE RACISM AND
ETHNICITY

AND THAT I WAS ASKED TO SPEAK BEFORE ROSALYN CARTER'S MENTAL
HEALTH SYMPOSIUM.

THE ISSUES ARE MORE THAN ACCESSIBILITY.

UNLESS WE LOOK AT THE PEOPLE WHO COME HERE NOT SPEAKING THE
LANGUAGE, SEPARATED FROM THEIR FAMILIES BECAUSE OF ESCAPE
FROM

THEIR COUNTRIES, WHETHER IT WAS FROM OPPRESSIVE, POLITICAL
OPPRESSION, COMMUNISM, YOU NAME IT.

THERE ARE 43 SEPARATE ETHNIC GROUPS IN THIS POPULATION.

AND OF THOSE GROUPS, WE ARE PILED TOGETHER UNDER ONE HEADING
AND

WE NO MORE HAVE ANYTHING COMMON THAN A POT OF RICE
SOMETIMES.

A COUPLE OF YEARS AGO, I WAS FORTUNATE ENOUGH TO BRING
TOGETHER

WITH FUNDING FROM THE CENTER FOR MENTAL HEALTH SERVICES A
GROUP

OF CONSUMERS TO ASK THEM WHAT THEY NEEDED IN TERMS OF
SERVICES

AND THIS IS WHAT THEY SAID: FAMILIES ARE VERY IMPORTANT,
BUT WE

NEED MATERIAL, INFORMATION, EDUCATIONAL PROGRAMS, AND INVOLVEMENT IN TREATMENT PLANNING FOR FAMILIES THAT IS CULTURALLY SENSITIVE, CULTURALLY LINGUISTICALLY APPROPRIATE. THAT WE NEED TREATMENT SERVICES, PROVIDER SERVICES THAT ARE BICULTURAL AND ALSO BILINGUAL.

IT'S NOT ENOUGH TO SPEAK THE LANGUAGE.

YOU HAVE TO KNOW THE CULTURE.

SHAME AND STIGMA IS GENERATIONS AND GENERATIONS OF PROFOUND ISSUES AROUND MENTAL ILLNESS.

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WELLNESS.
EDUCATION AND OUTREACH EFFORTS, SHOULD BE MADE AVAILABLE TO DISPEL SOME OF THE MYTHS THAT PROMOTE MORE EFFECTIVE

WE NEED PREVENTION AND EARLY INTERVENTION.

MOST IMPORTANTLY OF THIS GROUP OF THINGS THAT API CONSUMERS ADDRESS WAS THE NEED FOR PEER SUPPORT.

PEER SUPPORT IN ITS MOST PURE FORM IS THAT THAT IT'S SOMEONE THAT YOU CAN TALK WITH IN YOUR SAME LANGUAGE.

PEOPLE
IT'S SOMEONE THAT YOU SHARE SOMETHING COMMON BECAUSE THE

THAT ARE NEEDING THE SUPPORTS AND GETTING THE FREEDOMS TO GO BACK TO WORK, TO GET THE SERVICES, TO GO BACK TO SCHOOL, TO RETURN TO THEIR FAMILY, TO RETURN TO THE COMMUNITY, TO BE TAXPAYERS ARE THOSE WHOSE ACCESS ARE LIMITED BECAUSE OF LANGUAGE.

WOULD
SO I THANK YOU FOR THIS OPPORTUNITY TO COME TOGETHER AND

VALUING
LIKE TO CLOSE WITH THIS SAYING: VALUING DIVERSITY...

DIFFERENCES IS NOT ABOUT THE GOLDEN RULE, WHICH IS TREATING
OTHERS THE WAY YOU WISHED TO BE TREATED, BUT IT IS THE
PLATINUM
TREATED.
RULE, WHICH IS TREATING OTHERS THE WAY THEY WANT TO BE

I THANK YOU FOR THIS TIME.

I OFFER MY SERVICES IN BRIDGING THE GAPS OF COMMUNITY
EFFORTS

UNDER THE BUSH ADMINISTRATION AND THAT I WELCOME BEING A
PART OF
THAT IN THE STATE OF TEXAS WHERE I NOW RESIDE.

THANK YOU.

>> THANK YOU, MS. BERMUDEZ.

IF I CAN, BEFORE WE GO TO MS. KING, IF I CAN ASK THOSE OF
YOU
WHO ARE IN THE ORANGE GROUP, THE LAST GROUP THAT WILL BE

205

TESTIFYING IN THIS SEGMENT, IF YOU COULD MOVE TO THE BACK OF
THE
ROOM, WE'D MUCH APPRECIATE IT.

MS. KING?

>>> I AM EFFIE KING, AND I DON'T WANT MY MOTHER TO GO TO --
AND
I DON'T WANT MY GRANDDAUGHTER TO GO THERE EITHER.

I WORRY A LOT ABOUT MY DAUGHTER HAVING SO MUCH TO DO AND SO
MANY
ACTIVITIES.

>> I'M MARILYN KING.

I'M EFFIE'S DAUGHTER.

AND SHE HAS -- EFFIE HAS STRUGGLED WITH RAVAGES OF
PARKISON'S

DISEASE.

SHE'S BEEN DIAGNOSED FOR OVER 22 YEARS NOW.

ATTEMPTED

WHILE SHE WAS STRUGGLING WITH THAT DISEASE, SHE ALSO

TO TAKE CARE OF HER GRANDDAUGHTER WHO IS DEVELOPMENTALLY
DISABLED, JILL.

WHILE HER DAUGHTER DIED OF BREAST CANCER.

SHE HAD CONTRIBUTED TO THE COMMUNITY.

SHE HAD TAKEN CARE OF FAMILY.

SHE TOOK CARE OF THE NURSERY IN THE CHURCH.

BUT SHE'S LOST THAT INDEPENDENCE NOW.

BUT SHE IS HERE TODAY TO SAY THAT SHE STILL WANTS TO MAKE AN
IMPACT AND THAT -- SHE'S HERE TO SAY I CAN MAKE A DIFFERENCE

AND

WE THANK YOU FOR THAT OPPORTUNITY THAT YOU HAVE GIVEN TO

HER.

SO "I" IS FOR I CAN MAKE A DIFFERENCE.

"M," THERE IS -- MAYBE WE SHOULD CONSIDER THAT THERE IS A

MORAL

QUESTION HERE.

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FORCED TO

THE PATTERN IN THE PAST HAS BEEN THAT PEOPLE HAVE BEEN

LEAVE THEIR HOMES, SEPARATE THEIR FAMILIES, GO INTO

AND

INSTITUTIONS, USE RESOURCES, BE SEPARATED FROM EMOTIONAL

SPIRITUAL SUPPORT, AND HAVE CHOICES TAKEN AWAY FROM THEM.

PART

WE APPLAUD THE FREEDOM INITIATIVE HERE AND WE HOPE TO BE A

OF SEEING THAT COME ABOUT.

NO
LIVING
BUT RIGHT NOW WHAT WE ARE FINDING IS THAT THERE IS LITTLE TO
FAMILY SUPPORT WHEN PEOPLE TRY TO HAVE AN ALTERNATIVE OF
AT HOME.
WE ARE IN TENNESSEE RIGHT NOW WHERE FAMILIES SAY THEY ARE
INTIMIDATED, THREATENED, THEY FEEL SEGREGATED AND UNINFORMED
ABOUT THE OPPORTUNITIES AND SERVICES THEY SEEK.
WE THINK THAT FAMILIES DESERVE -- THAT INDIVIDUALS DESERVE
THE
SAME RIGHTS AS OTHER PEOPLE, INDIVIDUALS WITH DISABILITIES.
WANTED TO
YET IN TENNESSEE WE WERE TOLD FOR EXAMPLE THAT WHEN WE
COULDN'T
TRAVEL HERE IF JILL DID HAVE A PERSONAL ASSISTANT, SHE
THE
TAKE HER ACROSS THE STATE LINE, AND SHE COULDN'T GET HELP ON
OTHER SIDE OF THE STATE LINE EITHER.
AND WE WERE TOLD THAT IF WE GO OUT OF THE STATE TO SEEK HELP
THAT WE DON'T GET IN TENNESSEE, THAT WE WILL LOSE OUR
OPPORTUNITY TO BRING HER BACK IN SOME TIME.
STATE,
THERE IS A THREAT THAT WE WON'T BE ABLE TO REENTER THE
EVEN THOUGH MY MOTHER'S LIFE MIGHT DEPEND ON THAT HAPPENING.
WE WONDER ABOUT PEOPLE WHO HAVE SECOND HOMES.
WE KNOW THAT HAPPENS IN THE GENERAL POPULATION.
ARE PEOPLE WITH DISABILITIES NOT ALLOWED TO DO THAT?

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ARE THEY NOT ALLOWED TO LIVE IN TWO STATES?
IN TENNESSEE, THERE IS TALK OF INCLUDING FAMILIES.

IS A AND INCLUSION BY ITS VERY NATURE SEEMS TO IMPLY THAT THERE
POLICY OF EXCLUSION.
AND THERE IS A CIRCLE OF SUPPORT WHICH FOR MY NIECE, WHICH
MANDATES THAT IT INCLUDES THE PEOPLE FROM THE GOVERNMENT,
THE
PEOPLE WHO ARE FROM THE PROVIDER AGENCIES AND SO FORTH,
PEOPLE
WHO ARE BEING PAID TO PROVIDE SERVICES BUT WHO ARE NOT HER
CHOICES NECESSARILY AND PEOPLE WHO WOULD DETERMINE THE RIGHT
DIRECTION OF HER LIFE.
SO WE THINK THERE IS SOME CIVIL RIGHTS ISSUES MAYBE HERE
INVOLVED THAT WOULD DESERVE LOOKING AT, AND WE WOULD ASK
THAT
THE GOVERNMENT RE-EVALUATE ITS ROLE AND MAYBE IT WOULD BE
APPROPRIATE FOR THE GOVERNMENT TO STEP BACK AND SAY IT
SHOULD BE
TRAINING FAMILIES TO -- AND INDIVIDUALS TO CHOOSE THEIR OWN
DIRECTION, RATHER THAN INCLUDING THEM AS SO OFTEN IS THE
CASE
NOW.
AND "P" IN IMPACT IS FOR POLITICAL, MOVING FROM POLITICAL TO
PRACTICAL.
I AGONIZE OVER MY MOTHER HAVING TO LOOK DOWN ALL THE TIME
BECAUSE MEDICARE WON'T PAY FOR THE CHAIR THAT SHE NEEDS TO
RAISE
HER HEAD UP SO THAT SHE CAN SEE AT EYE LEVEL WITH EVERYONE
ELSE.
AND WHEN SHE CRIES OUT IN PAIN BECAUSE MEDICARE WON'T PAY
FOR
THE MATTRESS THAT SHE NEEDS UNTIL SHE GETS OPEN SORES, WHICH
OF
COURSE I'M NOT GOING TO LET THAT HAPPEN AND SHE CAN'T HAVE
THE

OF

PHYSICAL THERAPY THAT SHE NEEDS TO WARD OFF THE PROGRESSION

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THAT'S

THE DEGENERATIVE, INCURABLE DISEASE THAT SHE HAS BECAUSE
NOT PAID FOR.

WON'T

SHE STARVES FROM LACK OF NUTRITION BECAUSE THE DENTURES
WORK RIGHT, BUT MEDICARE WON'T PAY FOR THAT EITHER.

ASSISTANT

IF MY NIECE HAD A PERSONAL ASSISTANT, THAT PERSONAL

THAT

COULD PREPARE HER FOOD BUT NOT THE FOOD FOR MY MOTHER AND

VERY

WOULD NECESSITATE TWO PEOPLE IN THE SAME HOME, WHICH ISN'T
PRACTICAL.

TO

THE TRANSPORTATION IF IT WERE AVAILABLE WOULD TAKE MY NIECE

200

THE DOCTOR AND THEN BACK, EVEN THOUGH WE MIGHT HAVE DRIVEN

EAT

MILES TO GET THERE, WE COULDN'T SHOP, WE COULDN'T GO OUT TO

AND I WOULD HAVE TO BE IN A CAR BEHIND HER.

PEOPLE

AT THE AIRPORT, WE HAD TO WAIT FOR A LONG TIME BECAUSE

WHILE

WITH DISABILITIES HAD TO CALL AHEAD FOR AN ACCESSIBLE VAN

OTHERS WERE JUST JUMPING ON AND OFF AS THEY COULD.

IN TENNESSEE, POLITICAL APPOINTEES AND CONSULTANTS ARE BEING
PAID.

THE JOBS GO ON AND ON.

FOOD,

THE PEOPLE ARE -- IT'S BEEN DOCUMENTED THERE IS A LACK OF

THERE IS A LACK OF PROTECTION.

ONE COUPLE OF CONSULTANTS MAKES -- CLAIMS TO MAKE OVER
\$340,000

A YEAR, WHILE INDIVIDUALS SUFFER THE TERRIBLE CONDITIONS
THAT

THEY HAVE.

MY NIECE WAS IN ONE HOME WHERE FOUR PEOPLE WERE MURDERED.
SHE WAS IN ANOTHER HOME THAT RESULTED IN A BRUISE AND TWICE
AN

INFECTIOUS CONDITION THAT WAS UNNECESSARY IN THERE BECAUSE
OF

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NEGLIGENT CARE.

AND WHEN WE BROUGHT HER HOME BECAUSE OF PROBLEMS IN THE
STATE,

WE HAD NO HELP AT HOME AND I TAKE CARE OF BOTH OF THEM BY
MYSELF.

WE THINK THAT IT'S IMPORTANT AS WE TRANSITION FROM POLITICAL
TO

PRACTICAL TO CONSIDER PREVENTATIVE AND TO LOOK AT CHANGING
THE

ENVIRONMENT SO THAT PEOPLE CAN GET AROUND BETTER AND NOT
HAVE TO

DEPEND SO MUCH ON CAREGIVERS.

AND WHEN THEY DO, HAVE QUALITY OF CARE, RATHER THAN PEOPLE
RUNNING AROUND DOING JUST THINGS THAT COULD BE PREVENTED
BECAUSE

OF THE STRUCTURE.

SO WE WOULD CHALLENGE YOU TO HAVE A CONTEST WITH ARCHITECTS
TO

DESIGN SOME UNIVERSALLY ACCEPTABLE HOMES -- ACCESSIBLE
HOMES.

WE WOULD CHALLENGE YOU TO LOOK AT ZONING, INFLUENCING ZONING

TWO REGULATIONS TO ALLOW HOUSES TO HAVE TWO OR THREE KITCHENS,
OR THREE LIVING AREAS IN THE SINGLE FAMILY NEIGHBORHOODS SO
INDIVIDUALS COULD SHARE PRACTICALLY AND STILL BE A PART OF
AND MAINSTREAM COMMUNITY, THAT THEY COULD SHARE THE ENVIRONMENT
MAKE IT MORE ACCESSIBLE.
AND WE WOULD CHALLENGE YOU TO PREPARE THE COMMUNITY BY
EDUCATING PEOPLE IN INDUSTRIES LIKE RESTAURANTS AND HOTELS AND EVEN
GOING INTO CHURCHES TO ASSIST PEOPLE WITH SENSITIVITY TRAINING AND
THE COMMUNICATION SO THAT PEOPLE COULD HAVE MORE INVOLVEMENT IN
COMMUNITY.
AND THE "A" WOULD BE ACT NOW.
STUDY SO OFTEN WE HEAR WE NEED TO MEET ABOUT IT, TALK ABOUT IT,
210
IT, HAVE A PILOT PROGRAM.
WHEN PEOPLE'S NEEDS GO ON AND THEIR LIVES GO.
WHO AND SO WE WOULD ASK YOU TO EMPOWER OR AUTHORIZE INDIVIDUALS
ARE SENSITIVE AND WHO KNOW THE NEEDS OF PEOPLE TO JUST TO GO
AHEAD AND MEET THOSE NEEDS.
AND "C" WOULD BE FOR CONSUMER CHOICE.
MY THE CHOICES THAT WE HAVE HAD TO MAKE ARE THINGS LIKE IS IT
LIFE OR MY MOTHER'S, MY MOTHER'S OR MY NIECE'S?
WHO GETS A CHOICE HERE?

MORE
POSITION
THE
WITH
BRING
SYSTEM.

I HAVE SEEN THAT DONE VERY SUCCESSFULLY.
AND WE WOULD ASK YOU NOT TO ASSUME THAT THEY DON'T HAVE THE
RIGHT CREDENTIALS OR THAT THEY WON'T RELOCATE.
SO IF YOU COULD JUST LOOK AT MAKING ONE OF THE CREDENTIALS
THE
WOULD
TRAINING.
A
TOGETHER WE CAN TRAIN SO THAT WE CAN LEARN HOW TO IMPLEMENT
NEW DIRECTION.
IT'S LIKE TURNING A BUS AROUND IN THE MIDDLE A COUNTRY ROAD.
IT'S A BIG JOB, BUT TOGETHER WE CAN DO IT.
THANK YOU FOR YOUR TIME.

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>> THANK YOU VERY MUCH, EACH OF YOU, FOR YOUR TESTIMONY.
LET ME ASK THE NEXT GROUP OF PEOPLE WHO WILL BE PROVIDING
TESTIMONY TO PLEASE COME TO THE FRONT TABLE.
WHILE THEY ARE DOING THAT, LET ME TURN TO THE DIAS AND GIVE

THE MR. ENZEL THE OPPORTUNITY TO INTRODUCE HIMSELF, PLEASE, TO

GROUP.

MR. ENZEL, IF YOU WOULD PRESS THAT GREEN BUTTON THERE.

THANK YOU.

>> OH, I APOLOGIZE.

GOOD AFTERNOON, EVERYONE.

I'M DAVID ENZEL.

HOUSING I'M A DEPUTY ASSISTANT SECRETARY AT THE DEPARTMENT OF

AND URBAN DEVELOPMENT.

>> THANK YOU VERY MUCH.

MS. KAUFMAN, WE'LL GO TO YOU, PLEASE.

>> THANK YOU.

I AM CAROLYN KAUFMAN, AND I'M FROM PITTSBURGH, PENNSYLVANIA.

I'M A PERSON WITH BOTH A PHYSICAL AND A MENTAL HEALTH

DISABILITY, HAVING SURVIVED BOTH POLIO AND MAJOR DEPRESSION.

HAVE I ALSO HOLD A PH.D. FROM THE UNIVERSITY OF PITTSBURGH, AND

AND RECEIVED POSTDOCTORAL FELLOWSHIPS FROM VANDERBILT UNIVERSITY

UNIVERSITY THE WESTERN PSYCHIATRIC INSTITUTE AND CLINIC AT THE

OF PITTSBURGH.

MASTER'S OF I RECEIVED MY UNDERGRADUATE TRAINING AND I ALSO HOLD

SCIENCE AND MASTER'S OF ARTS DEGREES.

FLORIDA, I HAVE SERVED ON THE FACULTY OF THE UNIVERSITY OF SOUTH

UNIVERSITY.

THE UNIVERSITY OF PITTSBURGH, AND ALSO VANDERBILT

PANELS

AND CURRENTLY I AM WORKING ON ADVISORY GROUPS AND REVIEW

SECURITY

FOR THE CENTER FOR MENTAL HEALTH SERVICES, THE SOCIAL

CENTER

ADMINISTRATION, AND THE NATIONAL RESEARCH AND TRAINING

FOR PSYCHIATRIC REHABILITATION.

BUT I AM SPEAKING TODAY AS A PERSON WITH DISABILITIES.

MY TESTIMONY PRESENTS THREE POINTS.

PEOPLE

FIRST, DISCRIMINATION IS THE MAJOR BARRIER TO FREEDOM FOR

WITH MENTAL ILLNESS.

THE LIFETIME PREVALENCE OF PSYCHIATRIC DISEASE AMONG PEOPLE

LIVING IN THE U.S. IS ABOUT 49%.

EXPERIENCED

THIS MEANS THAT ALMOST HALF OF OUR POPULATION HAS

MENTAL ILLNESS SOME TIME DURING THEIR LIVES.

THE

MOST OF THESE ILLNESSES ARE RELATIVELY SHORT DURATION AND

PEOPLE SUFFERING FROM THEM RECOVER AND DO NOT HAVE SEVERE

IMPAIRMENTS.

COMPLETED

THIS IS DOCUMENTED BY THE NATIONAL STUDY THAT'S BEEN

KESSLER'S

BY THE NATIONAL INSTITUTES OF MENTAL HEALTH UNDER DR.

DIRECTION AT THE HARVARD UNIVERSITY.

WITH

DESPITE THIS, HOWEVER, THE DISCRIMINATION AGAINST PEOPLE

ARE

MENTAL ILLNESS IS SO GREAT THAT ONLY THE BRAVEST AMONG US

WILLING TO ADMIT THAT WE HAVE HAD ANY TYPE OF PSYCHIATRIC

DISORDER.

FEAR OF DISCRIMINATION PREVENTS THE MAJORITY OF PEOPLE WITH
MENTAL ILLNESS FROM SPEAKING PUBLICLY ABOUT THEIR
EXPERIENCE.

THERE ARE NO NEWSPAPER HEADLINES REPORTING THE
ACCOMPLISHMENTS

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OF PEOPLE WITH MENTAL ILLNESS.

THE BEST AMONG US ARE USUALLY IGNORED, WHILE A FEW
INDIVIDUALS

WHO COMMIT VIOLENT ACTS ARE GIVEN NATIONAL AND IN SOME CASES
INTERNATIONAL ATTENTION.

AS A RESULT, OUR COUNTRY IS NOT WELL PREPARED TO MEET THE
CURRENT AND FUTURE NEEDS OF PEOPLE WITH PSYCHIATRIC
DISABILITIES.

WE DON'T KNOW WHO THEY ARE.

THE NEW FREEDOM INITIATIVE CAN ADDRESS SOME OF THESE NEEDS
BY

IMPROVING SUPPORTS FOR PEOPLE WITH MENTAL ILLNESS.

I ASK IN ADDITION TO ADDRESSING THE ISSUES OF
DISCRIMINATION,

THAT THE FEDERAL -- THAT TWO FEDERAL PROGRAMS BE ENHANCED
UNDER

THE NEW FREEDOM INITIATIVE.

THEY ARE FIRST SUPPORTED EDUCATION FOR YOUNG ADULTS WITH
PSYCHIATRIC DISABILITIES.

AND SECOND, ASSISTED LIVING AND NURSING HOME SERVICES FOR
OLDER

ADULTS WITH SERIOUS AND PERSISTENT MENTAL ILLNESS.

BOTH GROUPS, YOUNG ADULTS AND SENIORS, SEEK SUPPORT FROM THE
EXISTING SYSTEM OF ADULT MENTAL HEALTH SERVICES.

OF

THAT SYSTEM NEEDS TO CHANGE IN ORDER TO MEET THE CHALLENGES
THE FUTURE.

YOUNG ADULTS WITH MENTAL HEALTH DISABILITIES HAVE DIFFERENT
EXPECTATIONS THAN THOSE OF THE PREVIOUS GENERATIONS.

ADVANCES IN DIAGNOSIS AND TREATMENT HAVE IMPROVED RATES OF
RECOVERY.

SIDE

NEWER PSYCHIATRIC DRUGS ARE MORE EFFECTIVE AND HAVE FEWER

214

YEARS

EFFECTS THAN THE OLDER TYPES OF MEDICATIONS.

PSYCHIATRIC HOSPITALIZATIONS ARE SHORTER THAN THEY WERE 20

USE

AGO AND PEOPLE WITH DEPRESSION CAN BE TREATED EFFECTIVELY BY
THEIR PRIMARY CARE PHYSICIAN AND CAN OFTEN AVOID EXTENSIVE

OF SPECIALTY PSYCHIATRIC CARE.

LIKE CANCER AND HEART DISEASE, MENTAL ILLNESS NOW CAN BE
REGARDED AS A TREATABLE HUMAN CONDITION.

IT DOES NOT CONDEMN THOSE WHO HAVE IT TO A LIFE OF MISERY.

PEOPLE WITH MENTAL ILLNESS MAY NOT RELISH THE EXPERIENCE OF
DESTRESS, BUT WE LEARN TO DEAL WITH IT.

WE GO ON AND WE LIVE OUR LIVES.

FIRST

MOST OF US CURRENTLY DIAGNOSED WITH MENTAL ILLNESS HAD OUR

SERIOUS EPISODES IN OUR LATE TEENS AND EARLY 20S.

IN

THIS IS THE TIME OF LIFE WHEN MOST YOUNG PEOPLE ARE EITHER

SCHOOL OR JUST ENTERING THE LABOR FORCE.

ARE

DISRUPTIONS IN EDUCATION OR CAREER TRAINING DUE TO ILLNESS

PARTICULARLY DIFFICULT FOR YOUNG ADULTS.
PEER GROUPS ARE OFTEN UNFORGIVING OF INDIVIDUALS WHO FALL
BEHIND
IN EDUCATIONAL ACHIEVEMENT.
ADOLESCENTS AND YOUNG ADULTS MAY BE LIMITED IN THEIR ABILITY
TO
OVERCOME SETBACKS.
WHEN ONE IS YOUNG AND IS JUST STARTING OUT IN THE ADULT
WORLD,
ONE SERIOUS MISHAP CAN FEEL LIKE A PERMANENT CALAMITY.
IT IS VERY HARD TO PICK UP THE PIECES AND GO ON.
SUPPORT OF EDUCATION FOR YOUNG ADULTS WITH SERIOUS MENTAL
ILLNESS IS ONE SHORT-TERM INVESTMENT THAT LEADS TO A
LIFETIME OF

215

IMPROVED EARNINGS AND PRODUCTIVITY FOR ALL AMERICANS.
EDUCATED PEOPLE WITH DISABILITIES ARE MORE ABLE TO COMPETE
IN
THE WORKPLACE AND MAINTAIN THEIR INDEPENDENCE THROUGHOUT
THEIR
LIVES.
YOUNG ADULTS WITH PSYCHIATRIC DISABILITIES DESERVE THE
OPPORTUNITY TO COMPLETE THEIR FORMAL EDUCATION IN TANDEM
WITH
THEIR RECOVERY FOR MENTAL ILLNESS.
THESE TWO ENDEAVORS ARE NOT CONTRADICTORY.
THEY COMPLIMENT ONE ANOTHER.
UNDERSTANDING OF ONE SELF COMES WITH INCREASING KNOWLEDGE OF
THE
WORLD.
AND IN PSYCHIATRY, AS IN RETAIL, AN EDUCATED CONSUMER IS OUR

BEST CUSTOMER.

MY FINAL POINT REGARDS OLDER PEOPLE.

HEALTH
THE AGING OF AMERICA HAS A DIRECT IMPACT ON ADULT MENTAL

DIAGNOSES
SERVICES IN TWO WAYS: FIRST, PEOPLE WITH PSYCHIATRIC

ARE LIVING LONGER.

MENTAL
ALTHOUGH RECENT STUDIES SUGGEST THAT PEOPLE IN THE PUBLIC

PEOPLE
HEALTH SYSTEM MAY HAVE SHORTER LIFE EXPECTANCIES, MOST

WITH SERIOUS PSYCHIATRIC CONDITIONS LIVE TO OLD AGE.

MENTAL ILLNESS CAN BE DISABLING, BUT IT IS NOT NECESSARILY
FATAL.

AND
THOSE WHO SURVIVE INTO THEIR 60S AND 70S FACE THE ISSUES OF
DECLINING PHYSICAL HEALTH AND THE NEED FOR ASSISTED LIVING

COMMUNITY-BASED SUPPORT AS DO OTHER SENIORS.

IMPAIRMENTS
AT THE SAME TIME, OLDER ADULTS CAN DEVELOP MENTAL

216

LATE IN LIFE.

MANY NURSING HOMES AND ASSISTED LIVING FACILITIES AND
COMMUNITY-BASED SUPPORTS ARE FACING THE PROBLEM OF PROVIDING
CARE FOR A NEW GENERATION OF ADULTS WHO ARE DIAGNOSED WITH
PSYCHIATRIC DISORDERS LATE IN LIFE.

NEEDS
EXISTING GERIATRIC SERVICES ARE NOT ADEQUATE TO MEET THE

OF THE GROWING POPULATION OF OLDER AMERICANS WITH MENTAL
ILLNESSES.

OTHER

PSYCHIATRIC PATIENTS WHO SEEK CARE IN NURSING HOMES AND

OBSTACLES

ASPECTS OF THE OLD AGE SERVICE SYSTEM FACE TREMENDOUS

TO GETTING THE CARE THEY NEED BECAUSE PROVIDERS ARE NOT
ADEQUATELY TRAINED OR READILY AVAILABLE.

>> MS. KAUFMAN?

>> YES?

>> IF I COULD ASK YOU IF YOU COULD WRAP UP, PLEASE.

>> I'M WRAPPING UP RIGHT NOW.

>> PERFECT.

THANK YOU.

CARE

>> PSYCHIATRIC -- THE NEW FREEDOM INITIATIVE CAN IMPROVE

HEALTH

FOR OLDER PEOPLE WITH MENTAL ILLNESS BY FUNDING MENTAL

SERVICES IN COMMUNITIES, NURSING HOMES, AND ASSISTED LIVING
FACILITIES.

TO SUMMARIZE, I ASK THE PRESIDENT AND CONGRESS TO INCLUDE

SUPPORTED EDUCATION, ASSISTED LIVING, AND DISCRIMINATION

OF

PROGRAMS FOR PEOPLE WITH MENTAL HEALTH DISABILITIES AS PART

THE NEW FREEDOM INITIATIVE.

217

THANK YOU.

>> THANK YOU, MS. KAUFMAN.

MS. PHILIANO?

OF

>> I'M HONORED TO PROVIDE AN ORAL TESTIMONY TODAY ON BEHALF

THE INDIVIDUALS THAT I WORK WITH IN BOSTON WHO EXPERIENCE

EMOTIONAL, COGNITIVE, AND PHYSICAL DISABILITIES AND I WOULD
LIKE
TO TAKE THIS OPPORTUNITY TO DISCUSS THE DIFFICULTIES
INVOLVED IN
TRANSITIONING FROM A PSYCHIATRIC INSTITUTION TO THE
COMMUNITY.
AS AN OCCUPATIONAL THERAPIST, I HAD THE OPPORTUNITY TO WORK
CLOSELY WITH INDIVIDUALS WHO ARE BEGINNING THE JOURNEY OF
DE-INSTITUTIONALIZATION.
IN ORDER TO ESTABLISH A CONCRETE AND EFFECTIVE COMMUNITY-
BASED
TREATMENT PLAN, THE EFFORTS MUST BEGIN WITH THE DISCHARGING
INSTITUTION.
A REQUEST OF CONSIDER TO INCLUDE MANDATORY LIFE SKILL
EVALUATIONS, FOR EXAMPLE, ACTIVITIES OF DAILY LIVING,
MEDICATION
MANAGEMENT, SOCIAL SKILL DEVELOPMENT, AND HEALTH AND
WELLNESS
MAINTENANCE AS PART OF THE DISCHARGE PAPERWORK PROCESS.
ONCE AN INDIVIDUAL HAS OFFICIALLY MOVED INTO A RESIDENTIAL
ENVIRONMENT, THEIR CONTINUED DEVELOPMENT IS CONTINGENT UPON
THE
ABILITY TO SUCCESSFULLY EXECUTE SKILLS THAT PROVIDE POSITIVE
FEEDBACK AND OUTCOMES.
HENCE, I'M ADVOCATING FOR THE ASSESSMENT OF LIFE SKILLS THAT
MAKE A HUMAN AN INDIVIDUAL AND IN TURN THAT THEY ARE PLACED
INTO
COMMUNITY-BASED HOUSING THAT IS SPECIFIC TO THOSE NEEDS AND
STRENGTHS.

ROBERT IS A 32-YEAR-OLD MALE WITH A DIAGNOSIS OF
SCHIZOPHRENIA

HAS AND HE ALSO EXPERIENCES A MILD FORM OF CEREBRAL PALSY AND HE
AND A BEEN LIVING IN A SKILLED NURSING FACILITY FOR THE LAST ONE
HALF YEARS.
AT THIS TIME FOR ROBERT, THE MOST IMPORTANT FOCUS OF HIS DAY
ESTEEM. REHABILITATION IS THAT HE IS ABLE TO INCREASE HIS SELF-
BUT MY QUESTIONS ARE WHY WAS ROBERT INITIALLY PLACED, AT 32
YEARS OLD, INTO A NURSING FACILITY AFTER HIS FIRST AND ONLY
PSYCHIATRIC HOSPITALIZATION?
WHY DID THE HEALTH SYSTEM RECOGNIZE HIS PHYSICAL DISABILITY
ONLY AND PLACE HIM IN AN ENVIRONMENT THAT DECREASES HIS CHANCE OF
AGE APPROPRIATE SOCIAL INTERACTIONS?
ROBERT AND HIS FAMILY ASKED THE SAME QUESTIONS, LOOKING TO
HIS HEALTH CARE PROVIDERS FOR ANSWERS, AND ALL WE CAN REPORT IS
THAT HE IS ON THE WAITING LIST FOR HOUSING.
LOSSES? WHO WILL TAKE RESPONSIBILITY FOR ROBERT AND HIS FAMILY'S
ESTEEM, LOSS OF TIME ON THE REHABILITATION CONTINUUM, LOSS SELF-
LOSS OF AUTONOMY, AND MOST IMPORTANTLY, LOSS OF A HEALTHY
QUALITY LIFE.
CONFERENCE AT THE ANNUAL NATIONAL ALLIANCE FOR MENTAL ILLNESS
HELD IN WASHINGTON, D.C. THIS JULY, THE U.S. SURGEON GENERAL
VICE REMIND US THAT WE CANNOT SEPARATE THE MIND FROM THE BODY OR
VERSA.
THE BEST TREATMENT WE CAN PROVIDE IS THAT WHICH IS HOLISTIC,

WITH AN EMPHASIS ON THE W-H.

IS TAKING INTO CONSIDERATION THE PHYSICAL EFFECTS OF EXPERIENCE

219

EFFECTS SERIOUS AND PERSISTENT MENTAL ILLNESS OR THE EMOTIONAL

OF PHYSICAL REHABILITATION AFTER UNDERGOING SOMETHING LIKE
OPEN-HEART SURGERY.

ROBERT'S STORY IS A CLASSICAL EXAMPLE OF HOW WE NEED TO
RECOGNIZE THE PHYSICAL, EMOTIONAL, AND COGNITIVE NEEDS OF
INDIVIDUALS WHO ARE ALREADY LIVING IN OUR COMMUNITIES.

ONLY PLACEMENT INTO A NURSING HOME FOR A 32-YEAR-OLD INDIVIDUAL

HOPE RESULTS IN THE DISCENTAGRATION OF HIS SENSE OF SELF AND HIS

FOR THE FURTURE.

WHO WILL PROVIDE THE MONEY AND SUPPORT FOR COMMUNITY HOUSING
WHERE THE FOCUS OF REHABILITATION IS ON THE WHOLE PERSON?

WHO WHERE ARE THE COMMUNITY ENVIRONMENTS FOR PEOPLE LIKE ROBERT

NEED ADA ACCESSIBLE OPTIONS, FLOOR PLANS THAT SUPPORT ENERGY
CONSERVATION AND ADAPTIVE EQUIPMENT THAT PROVIDES A DISABLED
INDIVIDUAL TO HAVE A KEEN SENSE OF AUTONOMY?

I ROBERT'S SCENARIO REPRESENTS A LARGE MAJORITY OF INDIVIDUALS

HAVE ENCOUNTERED IN THE MENTAL HEALTH SYSTEM IN BOSTON.

I URGE YOU TO CONSIDER LONG-TERM OUTCOMES OF CONTINUED
MISPLACEMENT OF INDIVIDUALS INTO THE COMMUNITY.

PERSONNEL MEMBERS OF THE PANEL, WHEN YOU ARE SITTING WITH YOUR

SUPERVISORS

AND REVIEWING TODAY'S EVENTS OR SITTING WITH YOUR

URGE

AND DISCUSSING THE FUTURE OF THE NEW FREEDOM INITIATIVE, I

REALLY

YOU TO RECALL UPON OUR FACES TODAY AND OUR STORIES AND

TAKE A MOMENT TO REFLECT UPON WHAT THE WORD "FREEDOM" MEANS.

THANK YOU.

>> THANK YOU VERY MUCH.

220

MS. STIME?

>> YES.

HELLO, MY NAME IS LAUREL STIME.

FOR

I'M THE DIRECTOR OF FEDERAL RELATIONS FOR THE BASLAN CENTER

HERE

MENTAL HEALTH LAW, A NATIONAL LEGAL ADVOCACY ORGANIZATION

DISORDERS

IN D.C. THAT REPRESENTS INDIVIDUALS WITH PSYCHIATRIC

WHO PRIMARILY RELY ON THE PUBLIC MENTAL HEALTH SYSTEM.

WE HAVE SUBMITTED WRITTEN COMMENTS, AND WITH THE FEW MOMENTS

FEW

THAT I HAVE TODAY, I WILL BE ABLE TO SHARE WITH YOU ONLY A

OF OUR RECOMMENDATIONS FOR CHANGE.

FIRST OF ALL, THE MEDICAID REHAB OPTION.

STATES

WE RECOMMEND THE DEPARTMENT ISSUE A POLICY MEMORANDUM TO

TO

CLARIFYING THE FULL ARRAY OF SERVICES THAT CAN BE FURNISHED

CHILDREN AND ADULTS WITH MENTAL AND EMOTIONAL DISABILITIES.

MANY STATES CONTINUE TO BE UNSURE ABOUT HOW TO COVER

INNOVATIVE,

REHAB EVIDENCE-BASED COMMUNITY MENTAL HEALTH SERVICES UNDER THE
OPTION SUCH AS PSYCHIATRIC REHABILITATION.
SUCH GUIDANCE WILL GIVE THE STATES THE FLEXIBILITY THEY NEED
TO PROVIDE COMMUNITY-BASED MENTAL HEALTH SERVICES AT FAR LESS
COST THAN HOSPITALIZATION AND WITHOUT THE GREAT RISK ASSOCIATED
WITH REPEALING THE IMD EXCLUSION.
REJECT THE ARGUMENT THAT THE IMD EXCLUSION IS A BARRIER TO
OLMSTEAD IMPLEMENTATION.
BY DENYING CARE FOR LONG-TERM HOSPITALIZATION IN LARGE
OR INSTITUTIONS AND PROVIDING TREATMENT IN COMMUNITY FACILITIES
AND SMALLER FACILITIES WHICH TEND TO PROVIDE SERVICES QUICKLY

221

SPENT IN MOVE PEOPLE INTO THE PLACEMENT, FEDERAL MONEY IS BETTER
INDIVIDUALS WITH DISABILITIES ARE SERVED IN THE COMMUNITY.
MAINTAIN THIS EXCLUSION.
MOVE STATES SHOULD BE ABLE TO USE HOME AND COMMUNITY WAIVERS TO
CHILDREN WITH SEVERE EMOTIONAL DISTURBANCES OUT OF 24-HOUR
RESIDENTIAL TREATMENT FACILITIES AND INTO HOME- AND
COMMUNITY-BASED SERVICES.
WAIVER HOWEVER, THE DEPARTMENT'S CURRENT INTERPRETATION OF THIS
STATUTE HAS REQUIRED CHILDREN WITH SED TO REMAIN
THEY INSTITUTIONALIZED IN RESIDENTIAL TREATMENT FACILITIES SO

CAN CONTINUE TO QUALIFY FOR MEDICAID.

FOR EXAMPLE, THE DEPARTMENT HAS RECENTLY REJECTED A WAIVER
FROM

THE STATE OF MARYLAND WHICH WOULD HAVE BEEN USED TO SERVE
CHILDREN WITH DISABILITIES WHO MEET THIS LEVEL OF CARE.

THIS INTERPRETATION PREVENTS MANY STATES FROM TAKING
ADVANTAGE

OF THIS WAIVER PROGRAM FOR CHILDREN WITH SERIOUS EMOTIONAL
DISTURBANCES.

THIS RESTRICTIVE READING OF THE WAIVER STATUTE CAN ALSO BE
APPLIED TO THE 134 OPTION.

WE UNDERSTAND OCR WITHIN HHS IS IN THE PROCESS OF DEVELOPING
MODEL ASSESSMENT TOOLS TO ASSIST WITH DETERMINATIONS OF WHEN
AN

INDIVIDUAL WITH A DISABILITY MAY APPROPRIATELY BE SERVED IN
THE

COMMUNITY AND WHAT SERVICES ARE REQUIRED.

WE URGE HHS TO ENSURE THAT ANY SUCH ASSESSMENT TOOL ALSO
FOCUS

ON THE NEEDS OF INDIVIDUALS, ADULTS, AND CHILDREN WITH
MENTAL

ILLNESS AND THE NEEDS OF INDIVIDUALS IN DIFFERENT AGE GROUPS
IN

222

ADDITION TO THOSE WITH DEVELOPMENTAL DISABILITIES.

WE ALSO SUPPORT AND RECOMMEND ADEQUATE FUNDING FOR THE
REGIONAL

DEPARTMENT OF JUSTICE AND OCR WITHIN HHS SO THAT THE
OFFICES HAVE ENOUGH STAFF AND RESOURCES TO EFFECTIVELY
INVESTIGATE COMPLAINTS.

FURTHERMORE, ISSUING CLEAR TIMEFRAMES FOR OLMSTEAD
COMPLIANCE

REVIEWS WILL GO A LONG WAYS TOWARDS MAKING OLMSTEAD
IMPLEMENTATION A PRIORITY.

LASTLY, I WOULD LIKE TO SAY WE ARE VERY EXTREMELY CONCERNED
ABOUT THE HIFA, HEALTH INSURANCE FLEXIBILITY AND
ACCOUNTABILITY

WAIVER.

WITHOUT NEW MONEY AND UNDER THE BUDGET NEUTRALITY, STATES
WILL

ONLY BE ABLE TO EXPAND COVERAGE FOR UNINSURED BY CUTTING
BENEFITS AND RAISING COST SHARING FOR CURRENT BENEFICIARIES

SO

THE VERY POPULATIONS THAT ARE LIKELY TO BENEFIT FROM THIS

NEW

FREEDOM INITIATIVE WILL BE HARMED AND THE SERVICES THAT THEY
NEED TO AVOID NEEDLESS INSTITUTIONALIZATION WILL BE CUT AND

NO

LONGER THERE.

THANK YOU VERY MUCH FOR YOUR TIME.

>> THANK YOU VERY MUCH, MS. STIME.

MS. WILLIAMS, WE GO TO YOU, PLEASE.

>> MY NAME IS MARY WILLIAMS.

I'M A REGISTERED NURSE.

AND OVER THE PAST 18 YEARS, I HAVE DEVELOPED A COMMUNITY
REINTEGRATION PROGRAM AS AN ALTERNATIVE TO INSTITUTIONAL
CARE.

WE PROVIDE EDUCATION, TRAINING, AND LONG-TERM CARE TO SPINAL

223

CORD INJURED CHILDREN AND ADULTS WHO HAVE THE SAME
DISABILITY AS

CHRISTOPHER REEVE.

LIFE.

WE HAVE SEEN CHRISTOPHER REEVE CONTINUE AN ACTIVE ROLE IN

HE LIVES WITH HIS FAMILY.

THE

AND WE COULD NEVER IMAGINE HIM LIVING IN A NURSING HOME FOR

REST OF HIS LIFE.

TRAGICALLY, MANY HAVE NO CHOICE.

AND UNTIL WE PUT A SOLUTION INTO ACTION, WE WILL CONTINUE TO

FALL SHORT OF MEETING OUR DISABLED POPULATIONS NEED.

TAKING

NEW START IS ONE SOLUTION FOR THOSE WHO ARE CAPABLE OF

THE

CONTROL OF THEIR OWN LIFE IN ORDER TO LIVE INDEPENDENTLY IN

COMMUNITY.

IT IS A COST-EFFECTIVE SOLUTION AND WE CAN SAVE BILLIONS OF

GOVERNMENT DOLLARS.

HERE IS AN EXAMPLE.

JESSICA, CHRISTIAN, SARAH, PYE, ARISALE, JUAN, AND D.J. ARE

SEVEN YOUNG CLIENTS CURRENTLY RESIDING AT NEW START.

THEY RANGE FROM 17 TO 34 YEARS OLD.

TOTAL

BEFORE COMING TO NEW START, THE GOVERNMENT ACTUALLY PAID A

PEOPLE

OF 52 YEARS OF INSTITUTIONAL CARE FOR THESE SEVEN YOUNG

AT A COST OF ABOUT \$28.5 MILLION.

EQUIVALENT

ON THE OTHER HAND, THE COST TO THE GOVERNMENT FOR AN

8.5

52 YEARS WHICH THEY HAVE SPENT AT NEW START HAS TOTALED ONLY

MILLION.

WE HAVE SERVED OVER A HUNDRED CLIENTS OVER THE 18 YEARS.

THIS MEANS THAT THE NEW START PROGRAM HAS ALREADY SAVED MORE

THAN A QUARTER OF A BILLION DOLLARS IN GOVERNMENT FUNDING.
WE HAVE LEARNED TO GIVE HIGH-RISK COMPLEX PATIENTS AN
IMPROVED
QUALITY OF LIFE.
FIVE OF THOSE YOUNG CLIENTS GRADUATED FROM HIGH SCHOOL AND
TWO
ARE STILL STUDENTS.
THEY ALL CAN USE A COMPUTER.
THEY LOVE GOING TO THE MOVIES, SHOPPING AT THE MALL, AND
THEY
DREAM THAT ONE DAY THEY WILL MOVE INTO THEIR OWN HOME, EARN
MONEY BY GETTING A JOB AND HAVE CHOICES JUST LIKE YOU AND I.
AFTER ALL, A 17-YEAR-OLD COULD LIVE ANOTHER 50 YEARS.
THE NEW START PROGRAM IS A MODEL TO BE TESTED.
HOWEVER, WE NEED OUR GOVERNMENT'S HELP IN REMOVING THE
BARRIERS
THAT MAKE IT SO DIFFICULT FOR US TO FUNCTION AND ADMIT NEW
PATIENTS.
BEN, ANDY, FRANKIE, AND KATHERINE ARE JUST A FEW OF THOSE
WHO
HAVE NO HOPE OF DISCHARGE FROM AN INSTITUTION.
ALREADY THEY HAVE SERVED 10 YEARS OF INSTITUTIONAL CARE
BETWEEN
THEM AND ARE WAITING TO ENTER THE NEW START PROGRAM.
THE MAJOR BARRIERS, AND THESE ARE SOME OF THEM THAT WE ARE
STILL
FACING, IS INFLEXIBLE HOME AND COMMUNITY WAIVERS, LACK OF
FUNDING FOR TRANSPORTATION, NO ACCESS TO RENTAL SUBSIDY
FUNDING,
ALTHOUGH WE ALL KNOW IT'S SUPPOSED TO BE THERE.

PILOTS

NO METHOD FOR ADOPTING INNOVATIVE PROGRAMS THAT WORK AS
FOR STATE AND FEDERAL EVALUATION.

OLMSTEAD

IN CONCLUSION, NEW START MEETS ALL THE REQUIREMENTS OF
AND WE ARE READY TO SERVE THOSE WHO WISH TO LIVE INSTEAD OF

225

SPEAKING

MERELY EXISTING IN INSTITUTIONS.

JACK ALLISON, A GRADUATE OF NEW START PROGRAM, WILL BE

LATER ABOUT HOW OUR SOLUTION HELPED HIM.

THANK YOU FOR GIVING ME THIS OPPORTUNITY TO SHARE THIS
INFORMATION.

>> THANK YOU, MS. WILLIAMS.

AND THANK ALL OF THE PANELISTS FOR YOUR EXCELLENT TESTIMONY.

LET ME ASK THE NEXT GROUP OF PEOPLE PROVIDING TESTIMONY TO
PLEASE COME TO THE FRONT.

AND WHILE THEY ARE DOING THAT, MS. GOODMAN?

CAN WE COME TO YOU, PLEASE?

>> YES.

IS THIS ON?

>> IT IS.

>> MY NAME IS SUSAN GOODMAN.

SYNDROME

I'M DIRECTOR OF GOVERNMENT RELATIONS FOR NATIONAL DOWN
CONGRESS.

NATIONAL DOWN SYNDROME CONGRESS IS A GRASS ROOTS PARENT
ORGANIZATION WITH CHAPTERS ALL OVER THE UNITED STATES.

I ALSO SPEAK FROM PERSONAL EXPERIENCE.

I AM THE PARENT OF AN ADULT SON WITH AUTISM.

BASICALLY

I WON'T TELL YOU HOW OLD BECAUSE THEN YOU WILL KNOW

HOW OLD I AM, AND I DON'T WANT ANYBODY TO KNOW THAT HERE.

EFFORTS

I WOULD LIKE TO CONGRATULATE THE ADMINISTRATION ON THEIR

TO IMPLEMENT OLMSTEAD THROUGH THE NEW FREEDOM INITIATIVE.

I COMPARE SOME OF THE LIVING ARRANGEMENTS FOR PEOPLE WITH

226

DISABILITIES TO COLLEGE DORMS.

NONE

ALL THE ADVANTAGES -- DISADVANTAGES OF A COLLEGE DORM AND

OF THE ADVANTAGES.

HOW WOULD YOU LIKE TO LIVE THERE FOR THE REST OF YOUR LIFE?

AND THAT'S THE BEST SITUATION.

A

I WAS AT A MEETING WHERE A SELF-ADVOCATE WAS TALKING TO US,

HEALTH POLICY-TYPE PERSON.

HER

THE SELF-ADVOCATE HAS BEEN INSTITUTIONALIZED AT SOME TIME IN

LIFE.

SOME

THE HEALTH POLICY PERSON SAID TO, YOU KNOW, THERE IS REALLY

REALLY NICE PLACES IN NURSING HOMES NOW BECAUSE THEY MAKE IT

REGULAR

LIKE A REAL LIVING ARRANGEMENT, LIKE IT'S, YOU KNOW, A

YOU

LIVING ROOM AND A REGULAR KITCHEN AND YOU CAN COME AND GO AS

PLEASE.

AND THE SELF-ADVOCATE SAID TO HIM, OH, HOW WOULD YOU LIKE TO

MOVE INTO ONE?

WHICH WAS TOTALLY AN APROPOS COMMENT.

WE BELIEVE STRONGLY IN THE SELF-DETERMINATION OF INDIVIDUALS WITH DISABILITIES AND SELF-DETERMINATION FOUNDED ON THE CORE PRINCIPLES OF FREEDOM, AUTHORITY, SUPPORT, AND RESPONSIBILITY.

FREEDOM IS THE FREEDOM TO EXERCISE THE SAME RIGHTS AS ALL CITIZENS WITH DISABILITIES.

IN MY HYPOTHETICAL ON THE COLLEGE DORM, EVERYONE WHO LIVES IN A COLLEGE DORM NOWADAYS CAN COME AND GO PRETTY MUCH AS THEY PLEASE.

THEY A PERSON WITH A DISABILITY CAN'T COME AND GO PRETTY MUCH AS

227

PLEASE WHEN THEY LIVE IN AN INSTITUTIONAL SETTING.

THE CONTROL OF SUMS AND MONEY.

IN SPITE OF THE FACT THAT THEIR PARENTS ARE SUPPORTING THEM, COLLEGE STUDENTS USUALLY HAVE CONTROL OVER THEIR MONEY, ESPECIALLY WHEN DISCOVER SENDS THEM A CHARGE CARD.

BUT INDIVIDUALS WITH DISABILITIES CAN'T DEVELOP INDIVIDUAL BUDGETS, WHICH MOVE WITH THEM FROM PLACE TO PLACE.

THE SUPPORT -- PERSONS WITH DOWN SYNDROME NEEDS SUPPORT FROM WHO PEOPLE WHO THEY CAN CONTRACT WITH FOR SPECIFIC TASKS, NOT

SOMEONE ELSE CONTRACTS WITH FOR SPECIFIC TASKS.

AND RESPONSIBILITY TO USE -- WISE USE OF PUBLIC DOLLARS.

CONTRIBUTE THAT'S THE OBLIGATION OF PEOPLE WITH DOWN SYNDROME TO

TO THEIR COMMUNITIES IN MEANINGFUL WAYS.

COLLEGE STUDENTS EVENTUALLY HOPEFULLY WILL ALL CONTRIBUTE TO

THEIR COMMUNITIES IN MEANINGFUL WAYS.

PEOPLE WITH DISABILITIES, THEY WILL REMAIN IN THE
INSTITUTIONAL

ENVIRONMENT FOR THE REST OF THEIR LIVES.

SO PEOPLE WITH DOWN SYNDROME HAVE THE RIGHT TO BE TREATED AS
INDIVIDUALS, NOT BE DISCRIMINATED AGAINST AT WORK OR IN THE
COMMUNITY, MAKE INFORMED CHOICES ABOUT THEIR LIVES, WHERE TO
LIVE, WITH WHOM TO SOCIALIZE AND WHERE TO WORK, HAVE
OPPORTUNITIES TO SOCIALIZE WITHIN THE COMMUNITY, HAVE THE
NECESSARY SUPPORT TO ENABLE THEM TO MAKE RESPONSIBLE
CHOICES,

AND
SPEAK AND BE LISTENED TO, HAVE ACCESS TO COMMUNITY SERVICES
EDUCATION, HAVE PRIVACY, BE SAFE AND GROW INTO RESPONSIBLE
ADULTS.

228

IN ORDER FOR THIS TO HAPPEN, WE NEED SEVERAL THINGS.
WE NEED TO REMOVE THE TERRIBLE INSTITUTIONAL BIAS IN
MEDICAID

MONEY TOWARDS INSTITUTIONAL FUNDING.
WE NEED TO CHANGE THE WAY THAT MONEY IS DISTRIBUTED SO THE
MONEY
GOES TO THE PERSON AND THEIR FAMILY, NOT TO THE AGENCY.
THIS DOESN'T MEAN WE ARE GOING TO PUT SERVICE PROVIDERS OUT
OF
BUSINESS.

THEY'LL STILL HAVE BUSINESS.

THERE ARE STILL THINGS FOR PEOPLE TO DO, EXCEPT A DISABILITY
BUSINESS IS NOT A GOOD THING.

WE NEED FOR PEOPLE WHO PROVIDE THE SUPPORTS TO PEOPLE WITH

DISABILITIES TO BE COMPENSATED BETTER FINANCIALLY AND
NONMONETARILY INCENTIVES.

THE A LOT OF THE PEOPLE WHO WOULD GIVE MY SON SUPPORT DON'T HAVE
VOCABULARY HE HAS AND HE HAS A DEVELOPMENTAL DISABILITY.
THIS IS NOT GOOD.

FOR MY WE NEED TO WORK TO ELIMINATE WAITING LISTS IN THE STATE.
WE WAITED FOR 10 YEARS TO GET INDIVIDUAL SUPPORT SERVICES
SON.

RIGHT AND THAT ISN'T EVEN THE FULL BALL OF WAX.
AND THE NEXT THING WE NEED IS SOMETHING HE DOESN'T HAVE
NOW, AND THAT'S SAFE HOUSING FOR EVERYONE.

LIVE WE WANT PEOPLE WITH DOWN SYNDROME AND OTHER DISABILITIES TO
LIVE IN IN SAFE PLACES JUST LIKE WE WANT OUR NONDISABLED KIDS TO
SAFE PLACES.

THANK YOU VERY MUCH.

229

>> THANK YOU VERY MUCH, MS. GOODMAN.

MR. NELSON, WE GO TO YOU, PLEASE.

>> YES, THANK YOU.

TO ON BEHALF OF THE NATIONAL MENTAL HEALTH ASSOCIATION, I WANT
THANK YOU FOR THE OPPORTUNITY TO SUBMIT OUR TESTIMONY TODAY.
RANGE WE HAVE ALSO PUT IT FORWARD IN WRITING AND WE TOUCH ON A
ONE. OF ISSUES THAT I WANT TO HIT VERY BRIEFLY AND THEN FOCUS ON

AND WE TALK ABOUT HOUSING AND OF THE COST-OF-LIVING ADJUSTMENTS

SSI AND SSDI HAVE NOT KEPT PACE WITH THE INCREASING COST OF RENTAL HOUSING AND WHAT THAT'S DOING TO PRICE PEOPLE OUT OF COMMUNITIES THAT THEY COULD LIVE IN.

AND WE ASKED SSA TO REALLY LOOK AT EXPANDING THOSE PAYMENTS

IN SSI AND SSDI TO KEEP UP WITH THE COST OF INFLATION.

WE TALK ABOUT OTHER HOUSING PROGRAMS IN 811 AND SECTION 8 VOUCHERS.

PROGRAM WE TALK ABOUT EMPLOYMENT AND REVISING THE TICKET TO WORK

TO ALLOW FOR COMPETITIVE, REASONABLE AND PRACTICAL SYSTEM OF PAYMENT.

WE REALLY TALK ALSO A LOT ABOUT COMMUNITY-BASED SERVICES AND EFFORTS THAT WE COULD ENGAGE IN AT THE FEDERAL LEVEL TO

SUPPORT STATES AND ADOPTING MEDICAID OPTIONS TO PROMOTE COMMUNITY-

BASED CARE WITHOUT REMOVING THE IMD EXCLUSION.

FLEXIBILITY TALKING ABOUT HOME- AND COMMUNITY-BASED WAIVERS AND

IN THAT PROGRAM, THE REHAB OPTION.

MAKING SURE THAT STATES UNDERSTAND THAT ACCESS TO THE NEWEST

COST MEDICATIONS NOT ONLY SAVES LIVES, BUT IS ALSO IN THE END

230

EFFECTIVE BY REDUCING HOSPITALIZATION.

THAT TYPE OF ASSISTANCE TO STATES IS INVALUABLE.

WE ALSO TALK ABOUT KIDS, WE TALK ABOUT EARLY PERIODIC

SCREENING

ENFORCEABLE

DIAGNOSIS AND TREATMENT AND THE NEED TO MAKE THAT

STATES

ACROSS THESE STATES AND TO OFFER TECHNICAL ASSISTANCE TO

TO UNDERSTAND HOW TO DO THAT SCREENING WITHIN THAT FEDERALLY
MANDATED PROGRAM.

MENTAL

WE ALSO TALK ABOUT CHILDREN SERVICES AND INTEGRATION AND
INTERAGENCY TASK FORCE TO LOOK AT CHILDREN ACROSS FROM

THIS

HEALTH AND CHILD WELFARE AND PHYSICAL HEALTH AND JUSTICE AND
GETTING THESE GROUPS TOGETHER AND WHAT TYPE OF ASSISTANCE

EACH

BODY CAN PROVIDE LOOKING AT THE WHOLE CHILD, RATHER THAN

CHILD BY DISABILITY.

ALSO

BUT AS WE TALK ABOUT THESE THINGS AND THIS ENVIRONMENT, WE

ROOM

WANT TO TALK ABOUT THE 3,000 POUND GORILLA SITTING IN THE

WITH US.

SYSTEM

AND THAT IS INADEQUATE FUNDING AND A FINANCIALLY STRESSED

THAT IS REALLY NEAR BANKRUPTCY ACROSS COMMUNITIES.

NOW, WE TALK ABOUT FUNDING TO DO WHAT WE ARE TALKING ABOUT

TODAY.

BUT

TO SOME DEGREE, WE CAN LOOK AT THE EXISTING INSTITUTIONS,

FOR

CLEARLY FUNDING AND PSYCHIATRIC INSTITUTIONS IS INSUFFICIENT

THE LEVEL OF NEED WE HAVE ACROSS COMMUNITIES.

SHARE

MUCH OF THAT FUNDING IS TIED UP IN THE DISPROPORTIONATE

SYSTEMS

HOSPITALS THAT CANNOT BE TRANSFERRED TO COMMUNITY-BASED

AND IN EVERY STATE NEEDED AT THE COMMUNITY LEVEL GOES BEYOND

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THAT WHICH WILL BE AVAILABLE IN STATE INSTITUTIONS SIMPLY IN
TRANSFERRING.

ALSO AS WE TALK ABOUT THIS PLANNING AND FINANCIAL INVESTMENT, WE

MUST BE CAREFUL NOT TO ADD TO THE BURDENS THAT MENTAL HEALTH
CONSUMERS AND COMMUNITIES ACROSS THE COUNTRY ARE ALREADY
FACING.

NEARLY 60,000 PEOPLE IN THIS COUNTRY ARE CURRENTLY IN STATE
PSYCHIATRIC HOSPITALS.

THE BUT THIS SIGNIFICANT NUMBER IS BY THE NUMBER OF PEOPLE ON

WAITING LISTS IN COMMUNITIES OR CURRENTLY RECEIVING POORLY
FUNDED AND INADEQUATE CARE, ON WAITING LISTS IN COMMUNITIES
AND

OF COULD BE BUMPED IF WE ARE NOT CAREFUL BY PEOPLE WE MOVE OUT
PSYCHIATRIC INSTITUTIONS, DESPITE LEVEL OF NEED.

NOT THESE ARE FOLKS WHO HAVE MET ELIGIBILITY CRITERIA OR HAVE

MET IT BECAUSE THE ELIGIBILITY CRITERIA HAS BEEN CREATED SO
TIGHTLY BECAUSE RESOURCES ARE SO FEW AT THE COMMUNITY LEVEL.
LET ME TELL YOU JUST A LITTLE BIT ABOUT HOW BAD THIS IS VERY
QUICKLY.

AND IF WE LOOK AT 1987 TO 1997 DATA, WE FIND THAT MENTAL HEALTH

SUBSTANCE ABUSE EXPENDITURES HAVE DROPPED BY 13% COMPARED TO
OVERALL EXPENDITURES FOR HEALTH CARE.

WHAT THEY WERE 10 YEARS AGO, THEY ARE NOW 13% OF THAT.

THE OVERALL REAL PURCHASING POWER OF STATES FOR STATE MENTAL

HEALTH AGENCIES BETWEEN 1955, TO GO BACK WHEN THEY FIRST
STARTED
TALKING ABOUT DEINSTITUTIONALIZATION IN MANY WAYS TO '97
DECLINED FROM 16.5 BILLION TO 11.5 BILLION.
AND TODAY, AS WE TALK ABOUT THESE NEEDS, WE NEED TO REMEMBER

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THAT MENTAL ILLNESS IS THE SECOND LEADING CAUSE OF
DISABILITY IN
THE UNITED STATES.
YET ONLY 7% OF ALL HEALTH CARE EXPENDITURES ARE DESIGNATED
FOR
MENTAL HEALTH DISORDERS.
THESE SOUND LIKE STATE ISSUES, BUT THEY ARE FEDERAL ISSUES
AS
WELL.
IN OUR TESTIMONY AND LETTERS TO THE ADMINISTRATION AND
LETTERS
TO CONGRESS, WE HAVE ASKED FOR EXPANSION OF THE MENTAL
HEALTH
BLOCK GRANT, THE CENTER FOR MENTAL HEALTH SERVICES YOUTH
SERVICE
ANTI-VIOLENCE INITIATIVE, THE CHILDREN'S MENTAL HEALTH
PROGRAM.
AND WE HAVE ALSO TALKED ABOUT PROGRAMS FOR REGIONAL AND
NATIONAL
SIGNIFICANCE.
THESE PROGRAMS TAKE THE SCIENCE AND MAKE IT WORK IN
COMMUNITIES.
MENTAL
THEY LOOK AT WHAT WE'VE DONE AT THE NATIONAL INSTITUTE OF
HEALTH AND SEE WHAT WE CAN EXPERIMENT WITH IN COMMUNITIES.
THIS ADMINISTRATION RIGHT NOW IN ITS BUDGET PROPOSE A \$16

MILLION CUT IN THAT PROGRAM.

YOU
SO AS WE TALK ABOUT WHAT WE NEED TO DO MORE, REMEMBER THE
FINANCIAL STRESS THAT WE ARE UNDER AND THIS WILL NOT BE --

KNOW, THIS WILL NOT BE A CHEAP ENDEAVOR.

THE
THIS IS ONE THAT NEEDS A LOOK VERY CLOSELY AT THE RESOURCES
THAT ARE CURRENTLY BEING PROVIDED AND SHOULD BE PROVIDED IN

FUTURE.

THANK YOU.

>> MR. NELSON, THANK YOU VERY MUCH.

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MR. BURK, WE GO TO YOU, PLEASE.

BARRIERS
>> THANK YOU FOR THE OPPORTUNITY TO COME BEFORE YOU TODAY TO
RESPOND TO PRESIDENT BUSH'S CALL TO ELIMINATE FEDERAL

SIGNIFICANT
TO COMMUNITY LIVING OPPORTUNITIES FOR PEOPLE WITH
DISABILITIES.

THE
I CURRENTLY SERVE AS DIRECTOR OF GOVERNMENT RELATIONS FOR

CREATE
CONSORTIUM OF DEVELOPMENTAL DISABILITIES COUNCIL, A NATIONAL
ASSOCIATION WITH MEMBERSHIP OF GOVERNOR'S COUNCILS ON
DEVELOPMENTAL DISABILITIES CHARGED UNDER FEDERAL LAW TO

DEVELOPMENTAL
POSITIVE SYSTEMS CHANGE WITH AND FOR PEOPLE WITH

DISABILITIES AND THEIR FAMILIES.

IN MY 25 YEARS OF WORK IN THE FIELD OF DEVELOPMENTAL
DISABILITIES, THE GREATEST SINGLE FEDERAL BARRIER I HAVE

ENCOUNTERED IS FOUND IN THE VAST DISPARITY BETWEEN WHAT THE
FEDERAL GOVERNMENT IS WILLING TO SPEND IF A FAMILY
INSTITUTIONALIZES A PERSON WITH A DISABILITY VERSUS WHAT THE
FEDERAL GOVERNMENT WILL EXPEND TO SUPPORT THE PERSON AT HOME
OR
IN A COMMUNITY SETTING.

I TRAVEL THIS NATION EVERY YEAR PROVIDING TRAINING SESSIONS
AND
LISTENING SESSIONS WITH PEOPLE WITH SEVERE DISABILITIES AND
THEIR FAMILIES.

MY OWN EXPERIENCE AND RESEARCH INDICATES THAT IF A FAMILY
INSTITUTIONALIZES ITS FAMILY MEMBER WITH A DEVELOPMENTAL
DISABILITY, THE GOVERNMENT IS WILLING TO EXPEND LARGE
AMOUNTS OF
TAXPAYER DOLLARS TO SUPPORT THIS PLACEMENT.

ON THE OTHER HAND, IF THEY DECIDE TO SUPPORT THEIR FAMILY
MEMBER

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AT HOME, THE FEDERAL GOVERNMENT SENDS THEM INTO A CYCLE
OFTEN
LEADING TO POVERTY.

FOR EXAMPLE, IN THE STATE OF GEORGIA, THE DEFENDANT STATE IN
THE
OLMSTEAD CASE, FOR A FAMILY THAT INSTITUTIONALIZED A FAMILY
MEMBER WITH A DISABILITY IN 1988, THE GOVERNMENT SPENT AN
AVERAGE OF \$765,459 TO COVER THIS PLACEMENT DURING THE
PERIOD
1989 THROUGH 1998 PER FAMILY.

FOR A FAMILY THAT DECIDED TO KEEP THEIR FAMILY MEMBER AT
HOME
OVER THIS SAME TIME PERIOD, THE GOVERNMENT EITHER SPENT
NOTHING,

SPENT A DRAMATICALLY SMALLER AMOUNT ON MONEY FOR DAY
PROGRAMS OR
SERVICE COORDINATION OR PLACED THE FAMILY ON A WAITING LIST
FOR
SERVICES.
THE AGE OLD JUSTIFICATION FOR THIS SITUATION IS THAT ONLY
QUOTE,
THE MOST SEVERELY DISABLED, UNQUOTE PEOPLE ARE SENT TO
INSTITUTIONS.
THIS IS SIMPLY NOT TRUE ANYMORE.
TODAY THERE IS VIRTUALLY NO DIFFERENCE BETWEEN THE LEVELS OF
IMPAIRMENT FOUND IN INDIVIDUALS IN INSTITUTIONS OR THOSE IN
THE
COMMUNITY.
WHILE THE OLMSTEAD DECISION WAS BASED ON THE PROVISIONS OF
THE
AMERICAN WITH DISABILITIES ACT, WE MUST REMEMBER THAT ONE OF
THE
FOUNDATIONS OF THE ADA IS THE EQUAL PROTECTION PROVISION
UNDER
THE UNITED STATES CONSTITUTION.
THIS ONGOING PATTERN OF DISCRIMINATORY TREATMENT AND FUNDING
UNDER MEDICAID INDICATES A PATTERN OF UNEQUAL PROTECTION,
NOT
ONLY UNDER THE ADA, BUT UNDER THE CONSTITUTION ITSELF.

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FEDERAL
ALMOST 30 YEARS AGO, RIGHT DOWN THE STREET FROM HERE,
DISTRICT JUDGE WADY FOUND THAT SUCH A PATTERN OF PROVIDING
GOVERNMENT FUNDS TO ONE GROUP AND NOT TO ANOTHER SIMILARLY
SITUATED GROUP CONSTITUTED A VIOLATION OF THE EQUAL
PROTECTION

CLAUSE.

THE IT WAS THE CASE OF MILLS VERSUS THE BOARD OF EDUCATION OF
DISTRICT OF COLUMBIA.

PARENTS HAD GONE TO THE COURT SEEKING EDUCATION FOR THEIR
CHILDREN WITH DISABILITIES.

TO THE DISTRICT HAD RESPONDED THAT IT SIMPLY DIDN'T HAVE MONEY
EDUCATION CHILDREN WITH DISABILITIES.

THE JUDGE RULED, IF SUFFICIENT FUNDS ARE NOT AVAILABLE TO
FINANCE ALL OF THE SERVICES AND PROGRAMS THAT ARE NEEDED AND
DESIRABLE IN THE SYSTEM, THEN THE AVAILABLE FUNDS MUST BE
EXPENDED EQUITABLY AND IN SUCH A MANNER THAT NO CHILD IS
ENTIRELY EXCLUDED FROM A PUBLICLY SUPPORTED EDUCATION.

ITS TAXPAYERS EXPECT THAT THE FEDERAL GOVERNMENT WILL DISTRIBUTE
RESOURCES EQUITABLY AMONG THOSE IN NEED.

THIS IS CERTAINLY NOT THE CASE UNDER THE CURRENT FEDERAL
MEDICAID POLICY.

THE MAJORITY GET VERY LITTLE OR NOTHING.

THEIR THEY ARE TRYING TO DO EVERYTHING THEY CAN DO TO PRESERVE
FAMILIES TO WORK HARD AND TO MAINTAIN IF NOT IMPROVE THEIR
QUALITY OF LIFE.

ASKING THEY ARE NOT ASKING FOR SPECIAL TREATMENT, THEY ARE NOT

TAKING FOR NEW HOUSES, THEY ARE NOT ASKING FOR TOTAL RELIEF FROM

CARE OF THEIR FAMILIES OR ANYTHING SPECIAL.

MEDICAID

THEY ARE ONLY ASKING FOR SIMPLE JUSTICE UNDER FEDERAL
POLICY.

OUR OWN U.S. CONSTITUTION SAYS WE MUST DO BETTER.
SIMPLE JUSTICE SAYS WE HAVE NO OTHER CHOICE.

THANK YOU.

>> THANK YOU VERY MUCH, MR. BURK.

MR. ALLISON, WE GO TO YOU, PLEASE.

>> GOOD AFTERNOON, LADIES AND GENTLEMEN.

THANK YOU FOR THIS INCREDIBLE OPPORTUNITY.

NEW
A FEW MINUTES AGO, YOU HEARD FROM MARY WILLIAMS, FOUNDER OF

SOUTHERN
START HOMES, AN INDEPENDENCE TRAINING ORGANIZATION IN
CALIFORNIA.

ANOTHER
I WOULD LIKE TO TALK ABOUT INDEPENDENCE TRAINING FROM
PERSPECTIVE.

I WAS THE ONE IN THE NURSING HOME.

UNDER
I WATCHED MY VERY STRONG FAMILY BUCKLE, FINALLY CRUMBLE
THE WEIGHT OF MY DISABILITY.

AFTER SEVEN MONTHS OF HOSPITAL REHAB THAT ATE UP MOST OF MY
MILLION DOLLAR INSURANCE POLICY, I WAS NOWHERE NEAR READY TO
COPE.

BUT AT THE NURSING HOME, SOMEONE NEW ABOUT NEW START.

A
MY INSURANCE COMPANY TOOK A RISK, WENT OUT OF POLICY, WROTE
CUSTOM CONTRACT WITH NEW START FOR SIX MONTHS OF CARE AND
TRAINING.

TO
AFTER JUST A COUPLE OF MONTHS WITH MY BED SORE BEHIND ME, SO

LEARNING SPEAK, AND MY DEPRESSION LIFTING, BEGAN TO LIVE AGAIN,
MY BODY, MY DOCTORS, MY MEDS,
OF MAKING SHOPPING LISTS, READING A BUS SCHEDULE, VENTURING OUT
MY CHAIR.
IN SIX MONTHS, I WENT FROM 24 HOURS OF LICENSED CARE IN A
NURSING HOME TO FOUR HOURS PER DAY UNLICENSED CARE IN MY OWN
HOME.
FOR MANY FRIENDS, SCOTT, SARAH, JESSICA, WITH MORE COMPLEX
MEDICAL INJURIES, THE STORIES AND THE COST SAVINGS MOSTLY FOR
ARE UNBELIEVABLE.
NEED FOR THOSE PEOPLE WAITING FOR OLMSTEAD TO BE REALIZED,, WE
VIEW TO MAKE SURE THAT IT PROVIDES MORE THAN JUST A DIFFERENT
OUT THE WINDOW.
THE DEPENDENCE ON 24-HOUR NURSING HOME CARE HAS TO END.
THE IN MANY CASES, GETTING PEOPLE OUT OF INSTITUTIONS AND INTO
COMMUNITY WON'T BE COMPLICATED OR EXPENSIVE.
STATE WITH INDEPENDENCE TRAINING PROGRAMS LIKE NEW START'S, WE CAN
HELP THE PERSON STRUGGLING TO PICK UP THE PIECES AND THE
STRUGGLING TO PICK UP THEIR TAB.
I AM A VOLUNTEER AT NEW START AND I WILL GIVE IT MY VOICE AS
LONG AS THE LORD PERMITS.
OF I SAVES LIVES LIKE MINE AND IT DOES SAVE INCREDIBLE AMOUNTS

MONEY.

DREAMS .
OLMSTEAD WOULD GIVE PEOPLE A CHANCE TO REACH FOR THEIR

LET'S GIVE THEM THE STRENGTH TO ACHIEVE THOSE DREAMS.

THANK YOU VERY MUCH.

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>> THANK YOU VERY MUCH, MR. ALLISON.

WE ARE GOING TO MOVE NOW TO MR. GRAY.

JOIN

BUT BEFORE WE TURN TO YOU FOR A SECOND, WE HAVE HAD SOMEONE

US AT THE DIAS AND I WANT TO GIVE HIM THE OPPORTUNITY TO
INTRODUCE HIMSELF.

SECTION

>> I'M JOHN WODATCH, THE CHIEF OF THE DISABILITY RIGHTS

AT THE DEPARTMENT OF JUSTICE.

>> SORRY, JOHN.

YOU ARE STILL JOHN WODATCH.

EXCUSE ME.

MR. GRAY?

OPPORTUNITY

>> I AGAIN, AS THOSE BEFORE ME TODAY, APPRECIATE THE

TO COME BEFORE YOU AND SPEAK.

COMMENTS.

I DO -- I WANT TO APOLOGIZE, I DON'T HAVE ANY WRITTEN

SO I GUESS BASICALLY I'M TELLING YOU YOU'RE GOING TO HAVE TO
LISTEN.

I DID NOT COME DOWN HERE TODAY WITH THE INTENT TO SPEAK.

I WANTED TO STICK MY HEAD IN AND SEE WHAT WAS GOING ON.

I AM THE EXECUTIVE DIRECTOR OF THE MARYLAND STATEWIDE

INDEPENDENT LIVING COUNCIL.

EACH STATE HAS ONE, EACH GOVERNOR APPOINTS ONE.

I'M ALSO THE CHAIR OF THE SILK CONGRESS, WHICH IS A
GATHERING OF

JOIN THE STATE INDEPENDENT LIVING COUNCILS ANNUALLY TO SHARE AND
TOGETHER IN ISSUES.

WHAT I HAVE TO SAY IS REALLY -- EVERYBODY HAS PRETTY MUCH
ONE POINTED OUT ALL THE BARRIERS AND I WOULD DARE SAY THAT NOT A

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ALL OF YOU HAS NOT LEARNED ANYTHING TODAY BECAUSE I THINK YOU

KNEW ALL THE BARRIERS BEFORE YOU GOT HERE.

WE ALL KNEW THEM.

WE HAVE KNOWN THEM FOR YEARS.

YOU MAY HAVE HEARD OF A FEW NUANCES OR MAYBE AN INDIVIDUAL
STORY, BUT WE HAVE KNOWN THEM.

STAY? THEY HAVE BEEN HERE AND THE QUESTION IS ARE THEY GOING TO

AS THE ADA IS A CIVIL RIGHTS ACT IN MY MIND AND IN MY SOUL AND

TO IT PERTAINS TO OLMSTEAD IN THE COMMUNITY, IT'S GOING TO HAVE

BE THAT WAY AND IT'S GOING TO HAVE TO BE PRESENTED AND
COMMUNICATED IN THAT WAY.

I DON'T FEEL LIKE IT'S BEEN DONE BY ANY ADMINISTRATION YET.

USED I HAVE NOT HEARD THE TERMS "SHAME, INTOLERABLE, UNAMERICAN"

THE WHEN WE TALK ABOUT INCARCERATING PEOPLE IN INSTITUTIONS FOR

CRIME OF HAVING A DISABILITY.

UNTIL THAT HAPPENS, NOTHING IS GOING TO HAPPEN.

THE LAST CIVIL RIGHTS ACT BEFORE THE ADA, WE HAD STATES GOVERNORS STANDING AT DOORS BARRING ENTRY.

I THINK WE HAVE POLICIES AND PROCEDURES AND PROCESSES
STANDING

INSIDE THE DOOR HOLDING US IN NOW.

AND IT'S GOING TO TAKE AN ACTION SIMILAR TO MAYBE WHAT
HAPPENED

IN THE MID '60S TO WALK THOSE PEOPLE OUT THOSE DOORS.

THAT'S NOT HAPPENED YET AND I DON'T SEE IT.

MAYBE YOU CAN NOW SEE WHY I DID NOT PLAN TO COME DOWN AND
SPEAK.

I REALLY FEEL THAT IT'S GOING TO TAKE THE LEADERSHIP OF THE PRESIDENT TO DO THIS AND THE REASON I'M VERY CYNICAL OF THAT

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HAPPENING IS BECAUSE THIS PRESIDENT AS GOVERNOR FOUGHT
AGAINST

WHAT WE ARE HERE ABOUT TODAY.

WHEN I SAY "FOUGHT AGAINST," HE WAS STILL ON THE OTHER SIDE
OF

ACCESS TO COMMUNITY.

AND I HOPE I'M WRONG.

I'M HOPING THERE HAS BEEN A CHANGE OF HEART AND I HOPE WE
ARE

SEEING IT HERE TODAY.

I'M HOPING THAT AFTER TODAY, THERE IS NOT A THREE-MONTH TIME PERIOD BETWEEN SUMMARIZING WHAT YOU HAVE LEARNED TODAY AND
THEN

A FOUR-MONTH PLAN TO MAKE A PLAN AND THEN A FIVE-MONTH PLAN HAPPEN.

BECAUSE I JUST HOPE THAT -- AND YOU HAVE TO USE THE WORD "HOPE"
BE I DON'T SEE IT YET IN ANY OTHER LIGHT THAT THIS IS GOING TO
THE BEGINNING OF A TRUE CHANGE, A REAL CHANGE.
I THANK YOU FOR YOUR TIME.
>> THANK YOU, MR. GRAY.
MR. GRISS?
>> HELLO, MY NAME IS BOB GRISS.
HERE IN I AM THE DIRECTOR OF THE CENTER ON DISABILITY AND HEALTH
WASHINGTON, D.C.
ONE OF THE MAIN ACTIVITIES OF THE CENTER IS TO TRANSLATE THE
ADA INTO NONDISCRIMINATION STANDARDS FOR HEALTH CARE DELIVERY.
HAS THIS IS FRANKLY A CHALLENGE THAT THE DEPARTMENT OF JUSTICE
NOT GOTTEN AROUND TO IN THE HEALTH CARE CONTEXT, NOR HAS IT
SHOWN UP IN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
REGULATIONS FOR MEDICARE OR MEDICAID.

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THE AND FRANKLY WE ARE SEEING CASES DEALING WITH ADA ARISING IN
PRIVATE HEALTH INSURANCE SYSTEM, MOST RECENTLY WITH THE
PIONEERING CASE THAT KAISER PERMANENTE SETTLED IN CALIFORNIA
WHERE THEY ADMITTED PROVIDING INFERIOR HEALTH CARE TO PEOPLE
WITH DISABILITIES BECAUSE THEY WERE NOT PROVIDING ACCESSIBLE
FACILITIES.
COMMUNITY THESE ARE VERY MAINSTREAM BARRIERS TO LIVING IN THE
FOR PEOPLE WITH DISABILITIES AND FOR PEOPLE WITHOUT

DISABILITIES.

AN AND I THINK IT ILLUSTRATES HOW PEOPLE WITH DISABILITIES HAVE

HEALTH INCREDIBLE OPPORTUNITY TO CONTRIBUTE TO CREATING A RIGHT TO HEALTH CARE IN THIS COUNTRY FOR EVERYONE BY GETTING THE GOVERNMENT TO TRANSLATE NONDISCRIMINATION STANDARDS FOR

CARE SO THAT WE ALL CAN BENEFIT FROM THAT.

AND HEALTH CARE IS A MAJOR BARRIER AND ADA CONSISTS OF NONDISCRIMINATION PRINCIPLES, BUT THEY NEED TO BE TRANSLATED

I WANT TO SUGGEST FOUR DIMENSIONS.

ONE OF THEM HAS TO DO WITH PHYSICAL ACCESSIBILITY.

THE KAISER PERMANENTE CASE IS AN EXAMPLE OF IT.

FACILITIES MANY PEOPLE FACE PHYSICAL BARRIERS ENTERING MEDICAL

HAVING HAVING A DOCTOR'S OFFICE WITHOUT ACCESSIBLE EXAM TABLES,

MANY DIFFICULTIES MOVING AROUND IN HEALTH CARE FACILITIES OR GETTING TO THEM.

THERE ARE ALSO COMMUNICATION ACCESSIBILITY BARRIERS.

FOR THIS COULD BE INTERPRETER SERVICES OR TRANSLATER SERVICES

PEOPLE WITHOUT DISABILITIES WHO SPEAK A DIFFERENT LANGUAGE.

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CAN HEALTH CARE IS VERY MUCH AN INDIVIDUAL NEED THAT OUR SYSTEM

RESPOND TO AND THE ADA PROVIDES PRINCIPLES FOR NONDISCRIMINATION.

IN THERE ARE CIVIL RIGHTS LAWS FOR CULTURAL MINORITIES AS WELL

TERMS OF CULTURAL COMPETENCE.

BE
AND I THINK THAT IF THE NEW FREEDOM INITIATIVE IS GOING TO
MEANINGFUL, IT WILL BE MEANINGFUL NOT JUST FOR PEOPLE WITH
DISABILITIES, BUT FOR THE TOTAL POPULATION.

OF
SO I AM LOOKING FOR THE WAY THE GOVERNMENT RESPONDS ON ALL
THESE ISSUES.

OF
THE THIRD ISSUE I WANT TO MENTION IS BENEFITS BECAUSE MANY
EVEN IN
THE BENEFITS -- HEALTH CARE BENEFITS ARE DISCRIMINATORY,

A PROGRAM LIKE THE MEDICARE PROGRAM.

THERE ARE RESTRICTIONS ON THE WAY NEEDS ARE DEFINED.

NOT
YOU CAN'T GET ACCESS TO DURABLE MEDICAL EQUIPMENT IF IT IS
USED OR NEEDED WITHIN THE HOME.

AN
THAT KIND OF BARRIER THAT'S EXISTED FOR THE LAST 35 YEARS IS

TO
EXAMPLE OF THE TYPE OF DISCRIMINATION THAT I THINK WE NEED
PROGRAMS.
ELIMINATE IN THE PUBLIC PROGRAMS AND IN THE PRIVATE

HEALTH
AND THE LAST ISSUE IS METHODS OF ADMINISTRATION, HOW IS
CARE ADMINISTERED?

ARRANGEMENTS
AND THIS REALLY COVERS A WHOLE RANGE OF SERVICES OF
PARTICULARLY IN MANAGED CARE.

ASSESSMENT
BUT THE ONE I WANT TO DEAL WITH FIRST AND ONLY IS THE
OF NEEDS, SCREENING AND ASSESSMENT OF NEEDS.

WHERE
AND I WANT TO DEAL WITH THIS BECAUSE THIS IS AN EXAMPLE OF

CONSUMER THE BUSH ADMINISTRATION HAS ELIMINATED A VERY IMPORTANT
THE PROTECTION IN THE MEDICAID MANAGED CARE REGS, EVEN THOUGH
MEDICAID PROGRAM AND PEOPLE WITH DISABILITIES IN MANDATORY
MEDICAID MANAGED CARE ARE A VERY VULNERABLE POPULATION.
CARE AND WHEN WE SEE THE FEDERAL GOVERNMENT SAYING THAT MANAGED
PLANS ARE NOT REQUIRED TO SCREEN ENROLLEES AND PROVIDE
THINK ASSESSMENTS IN A TIMELY WAY, I GET VERY WORRIED BECAUSE I
THIS WE ARE SETTING PEOPLE UP FOR DISCRIMINATION AND I FEEL THAT
IS THE KIND OF PROBLEM THAT SHOULD BE DEALT WITH
DIFFERENTLY.
BECAUSE MANY OF THE SPEAKERS HAVE TALKED ABOUT THE HIFA WAIVER
UNINSURED WE CLEARLY KNOW AND ARE EMBARRASSED BY THE 42 MILLION
ADMINISTRATION PEOPLE IN THIS COUNTRY AND I'M GLAD THAT THE BUSH
RECOGNIZE THAT IT'S A PROBLEM THAT HAS TO BE DEALT WITH.
OPTIONAL BUT THE HIFA WAIVER INVITING STATES TO REDUCE THE BENEFIT
PACKAGE FOR SO-CALLED OPTIONAL SERVICES, FOR SO-CALLED
WE POPULATIONS IS ITSELF AN INSULT TO THE AMERICAN PUBLIC AND
AVAILABLE WANT -- WE WANT TO SEE MEANINGFUL HEALTH CARE BENEFITS
TO EVERYONE WITH EQUAL OPPORTUNITY TO BENEFIT FROM COVERED
SERVICES BEING THE STANDARD THAT IS USED FOR PEOPLE WITH
DISABILITIES AND FOR PEOPLE WITHOUT.

THE LAST POINT I WANT TO MAKE IS THAT THERE IS A CONFLICT OF
INTEREST THAT THE STATE HAS AS THE PROTECTOR OF CONSUMER
RIGHTS
AND AS THE PAYER FOR MEDICAID SERVICES.
THAT'S WHY WE NEED FEDERAL STANDARDS, THAT'S WHY WE NEED
FEDERAL
OVERSIGHT.
AND THAT IS WHAT HAS BEEN ELIMINATED FROM THE HIFA
REGULATIONS

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WHICH DON'T EXIST.
THE HIFA WAIVER, I DON'T SEE THE FEDERAL SAFEGUARDS THERE.
I DON'T SEE THE LEVERAGE AND FROM THE MEDICAID MANAGED CARE
REGS
THAT HAVE BEEN GUTTED SPECIFICALLY IN RELATION TO PEOPLE
WITH
SPECIAL HEALTH CARE NEEDS.
THIS SENDS A VERY DANGEROUS SIGNAL THAT PEOPLE WITH
DISABILITIES
ARE NOT TO BE TAKEN SERIOUSLY IN THE HEALTH CARE CONTEXT.
AND I HOPE THAT THIS PROBLEM CAN BE ADDRESSED BY THE
ADMINISTRATION, BY CONGRESS, AND BY THE AMERICAN PUBLIC WHO
RECOGNIZE THAT THE ADA IS NOT FOR PEOPLE WITH DISABILITIES.
IT'S FOR PEOPLE WITH DISABILITIES AS A LITMUS TEST FOR THE
TOTAL
POPULATION SO THAT WE ALL HAVE A MEANINGFUL RIGHT TO HEALTH
CARE.
>> THANK YOU, MR. GRISS.
MR. BEDLIN?
>> GOOD AFTERNOON.
THANK YOU FOR THIS OPPORTUNITY.

MY NAME IS HOWARD BEDLIN.

I'M THE VICE PRESIDENT FOR PUBLIC POLICY AND ADVOCACY FOR
THE

NATIONAL COUNCIL ON THE AGING.

NCOA IS THE VERY FIRST SENIOR ORGANIZATION THAT WAS FORMED.

WE HAVE A DIVERSE MEMBERSHIP OF COMMUNITY SERVICE
ORGANIZATIONS

AND CONSUMER COALITIONS.

WE ALSO CO-CHAIR, ALONG WITH PARALYZED VETERANS OF AMERICA,
THE

COALITION ON DISABILITY AND AGING, WHICH BRINGS TOGETHER

ORGANIZATIONS REPRESENTING PERSONS WITH DISABILITIES AND
SENIORS

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TO LOOK AT AREAS OF COMMON INTEREST AND CONCERN.

THE COALITION'S NUMBER ONE PRIORITY IS IMPROVING ACCESS TO
ON
MEDICAID HOME AND COMMUNITY SERVICES AND I'M GOING TO FOCUS

THAT PRIMARILY TODAY.

MEDICAID CURRENTLY SPENDS ABOUT THREE TIMES MORE ON LONG-
TERM

INSTITUTIONAL CARE AS OPPOSED TO HOME AND COMMUNITY
SERVICES.

AND BECAUSE OF THIS BIAS, PEOPLE ARE FORCED INTO
INSTITUTIONS

PREMATURELY AS YOU HAVE HEARD TODAY.

HOME AND COMMUNITY SERVICES ARE LESS EXPENSIVE THAN NURSING
HOME

CARE.

THEY KEEP FAMILIES TOGETHER, THEY PROMOTE DIGNITY AND

INDEPENDENCE.

ONE ACCORDING TO A RECENT SURVEY, FOR EXAMPLE, AMERICAN'S NUMBER
NURSING WORRY ABOUT GROWING OLDER WAS LIVING FOR MANY YEARS IN A
HOME BECAUSE OF FRAILTY OR LONG-TERM ILLNESS.
I WOULD LIKE TO BRIEFLY SUMMARIZE OUR SPECIFIC TOP TEN
RECOMMENDATIONS FOR ADDRESSING THIS INSTITUTIONAL BIAS AND
IMPROVING ACCESS TO HOME AND COMMUNITY SERVICES.
NUMBER ONE, INCREASE THE FEDERAL MEDICAID MATCH FOR STATES
THAT ADOPT A RESOURCE MAINTENANCE ALLOWANCE TO HELP CLIENTS MEET
THE ASSET TEST UNDER MEDICAID.
IT MAKES NO SENSE THAT UNDER CURRENT LAW, THE ASSET TEST IS
IDENTICAL FOR HOME AND COMMUNITY SERVICES AND PEOPLE THAT
ARE IN NURSING HOMES.
PEOPLE IN NURSING HOMES DO NOT HAVE THE SAME OUT-OF-POCKET
EXPENSES AS THOSE IN THE COMMUNITY.

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HOME IT IS A HUGE PROBLEM THAT IS CREATING A MAJOR BARRIER TO
AND COMMUNITY SERVICES.
COMMUNITY SECOND, REMOVING THE ELIGIBILITY LINK BETWEEN HOME AND
SERVICES AND THE NEED FOR INSTITUTIONAL CARE.
IDENTICAL IF A STATE HAS TWO ACTIVITIES OF DAILY LIVING ELIGIBILITY
CRITERIA FOR NURSING HOME CARE, THEY HAVE TO HAVE THE
CRITERIA FOR HOME AND COMMUNITY SERVICES.
THIS MAKES ABSOLUTELY NO SENSE.

AND WE NEED TO GIVE STATES MORE FLEXIBILITY TO DIFFERENTIATE BETWEEN THOSE SETTINGS.

THIRD, INCREASING THE MEDICAID MATCH FOR STATES THAT ADOPT SPOUSAL IMPOVERISHMENT PROTECTIONS UNDER HOME AND COMMUNITY SERVICE PROGRAMS.

NURSING UNDER CURRENT LAW, SPOUSAL PROTECTIONS ARE MANDATORY FOR

HOME CARE, OPTIONAL FOR HOME AND COMMUNITY SERVICE WAIVER PROGRAMS AND NONEXISTENT FOR THE PERSONAL CARE PROGRAM. THAT'S OUTRAGEOUS AND UNACCEPTABLE.

ATTENDANCE FOURTH, PASSING S-1298, THE MEDICAID COMMUNITY-BASED

ADMINISTRATION SERVICES AND SUPPORTS ACT OR MICASO, WHICH I ASSUME YOU HAVE HEARD A LOT ABOUT TODAY, WE ARE HOPING THAT THE

THE WILL SUPPORT IT, MANY SENIOR GROUPS AND YOU KNOW ABOUT ALL THE DISABILITY GROUPS THAT SUPPORT IT.

WE'RE ONE IMPORTANT COMPONENT OF THAT IS THE \$50 MILLION IN SYSTEM CHANGE GRANTS, WHICH AS YOU KNOW WAS INACTED LAST YEAR AND

AND HOPEFUL THAT THE ADMINISTRATION WILL SUPPORT AGAIN THIS YEAR IN FUTURE YEARS.

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HOME FIFTH, REPEALING MEDICAID ESTATE RECOVERY AS IT APPLIES TO AND COMMUNITY SERVICES.

COMMUNITY MANY INDIVIDUALS WILL NOT APPLY FOR MEDICAID HOME AND

WHILE CARE BECAUSE THEY DON'T WANT A LIEN PLACED ON THEIR HOMES

THEY ARE STILL LIVING IN IT.

ANOTHER POLICY THAT MAKES NO SENSE AND CONTRIBUTES TO THE
CURRENT INSTITUTIONAL BIAS.

MEETING

SIXTH, PERMITTING STATES TO INCLUDE MEDICARE SAVINGS IN
THE BUDGET NEUTRALITY REQUIREMENTS OF THE HOME AND
COMMUNITY-BASED SERVICE WAIVER PROGRAM.

VARIETY

IN A RECENT HEARING BEFORE THE SENATE AGING COMMITTEE, A
OF STATE REPRESENTATIVES TESTIFIED BEFORE SENATORS BROWE AND
CRAIG ARGUING THAT THEY NEEDED TO HAVE THE FLEXIBILITY TO
INCLUDE MEDICARE SAVINGS TO MEET THIS BUDGET NEUTRALITY
REQUIREMENT.

SEVENTH, GREATER EMPHASIS TO ENCOURAGE STATES TO MOVE IN THE
DIRECTION OF CONSUMER DIRECTED SERVICES.

AS

NOT ONLY FOR YOUNGER PEOPLE WITH DISABILITIES, BUT SENIORS
WELL.

PERSONAL

SPECIFICALLY RIGHT NOW THERE ARE PROHIBITIONS IN CURRENT LAW
THAT DO NOT PROVIDE FEDERAL FINANCIAL PARTICIPATION FOR

FRIENDS.

CARE AND OTHER WAIVER SERVICES PROVIDED BY FAMILY AND

ARE

WE THINK THAT THIS IS A REAL PROBLEM AND WE ARE LOOKING AT
EXPANSIONS OF PERMISSION FOR STATES TO PAY FOR SERVICES THAT

APPROPRIATE FOR FAMILY AND FRIENDS TO DELIVER.

NUMBER EIGHT, FOCUSING GREATER ATTENTION ON THE SHORTAGE OF

AND FRONT-LINE AND OTHER POWER PROFESSIONAL WORKERS IN THE HOME-
COMMUNITY-BASED SERVICES AREA.
THIS IS A HUGE AND GROWING PROBLEM.
A GREAT DEAL OF ATTENTION HAS BEEN GIVEN TO THE SHORTAGE OF
NURSES AND HOSPITALS, NOT ENOUGH ATTENTION GIVEN TO POWER
PROFESSIONALS AND HOME COMMUNITY SERVICES.
DEPARTMENT I THINK AN IMPORTANT AREA FOR DEPARTMENT OF LABOR AND
DEPARTMENT OF HEALTH AND HUMAN SERVICES TO WORK TOGETHER BECAUSE IT'S
GOING TO GROW AND GET A GREAT DEAL WORSE OVER TIME.
FOR NINTH, I THINK I'M ON NINTH, INCREASE APPROPRIATIONS FUNDING
A VARIETY OF PROGRAMS, SECTION 202 HOUSING, TITLE 20 SOCIAL
SERVICES BLOCK GRANT AND PARTICULARLY OLDER AMERICAN'S ACT
PROGRAM.
AND NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM AND TRANSPORTATION
OTHER SUPPORTIVE SERVICES UNDER TITLE III OF THE OLDER
AMERICAN'S ACT.
TO TRANSPORTATION IS A HUGE PROBLEM FOR SENIORS TO ENABLE THEM
IN LIVE IN THE COMMUNITY AND A GREAT DEAL MORE NEEDS TO BE DONE
THAT AREA.
I COULD GO ON AND ON ABOUT CAREGIVER PROBLEMS.
I WON'T.
PROBLEMS BUT BELIEVE ME WHEN I TELL YOU THAT THERE ARE ENORMOUS
MORE THAT AMERICA'S CAREGIVERS ARE FACING AND THEY NEED A LOT
HELP THAN THEY ARE GETTING RIGHT NOW.

AND

LAST, WE VERY MUCH SUPPORT LEGISLATION TO PROVIDE CAREGIVERS
THOSE NEED WITH A \$3,000 TAX CREDIT, BIPARTISAN LEGISLATION

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INTRODUCED BY SENATOR GRASSLY, CONGRESSWOMAN JOHNSON AND WE
WOULD LIKE THE ADMINISTRATION TO SUPPORT THAT.

ABOUT A

TWO FINAL THOUGHTS, ONE IS ONE OF THE BEST SOURCES OF
INFORMATION ON THE INSTITUTIONAL BIASES IS A REPORT DONE

STATUTES

YEAR AND A HALF AGO OUT OF THE UNIVERSITY OF CALIFORNIA, SAN
FRANCISCO BY CHARLENE HARRINGTON AND OTHERS ON FEDERAL

BASED

AND REGULATIONS FOR PERSONAL CARE AND HOME- AND COMMUNITY-

BUT

SERVICES IT LOOKS NOT ONLY AT LEGISLATIVE RECOMMENDATIONS

REGULATORY AREAS AS WELL AS RESEARCH.

HAS

WE STRONGLY SUGGEST THAT FOLKS REVIEW THAT PAPER BECAUSE IT

SOME GREAT MATERIAL IN IT.

FINALLY, I'M A LITTLE BIT SURPRISED AND DISAPPOINTED QUITE

FRANKLY THAT NOT MORE SENIOR ORGANIZATIONS ARE HERE TODAY.

WE THINK THAT A GREAT MORE CAN BE DONE AND SHOULD BE DONE TO

REACH OUT TO SENIOR GROUPS.

NATIONAL SENIOR ORGANIZATIONS ARE VERY, VERY INTERESTED IN

IMPROVING ACCESS TO COMMUNITY LIVING AND WE WOULD BE VERY

INTERESTED IN HELPING TO REACH OUT TO THOSE ORGANIZATIONS.

THANK YOU.

>> THANK YOU VERY MUCH, BOTH OF YOU GENTLEMEN.

I'M GOING TO STAND AT THIS POINT.

HOPEFULLY THIS MIKE IS WORKING.

WE HAVE JUST CONCLUDED THE END OF THE PUBLIC TESTIMONY
PORTION

OF THE AGENDA.

I THINK WE HAVE HAD DURING THE COURSE OF THE DAY AN
INCREDIBLY

RICH AND USEFUL SORT OF INFORMATION THAT'S BEEN SHARED BY
PEOPLE

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WHO HAVE COME TO TESTIFY.

WE'RE NOW GOING TO MOVE INTO THE OPEN MIC SESSION.

WE WHAT WE WOULD LIKE TO DO, WE WILL HAVE SOME MICS AROUND
THE

ROOM.

AND WE WOULD LIKE TO GIVE YOU THE OPPORTUNITY TO ADD TO
COMMENTS

THAT YOU HAVE MADE DURING THE COURSE OF THE DAY, OR JUST PUT
OTHER ISSUES OUT ON THE TABLE THAT YOU WOULD LIKE TO SHARE

WITH

THE FEDERAL OFFICIALS THAT ARE ON THE DIAS AND AROUND THE

ROOM.

WE ARE EXPECTING SECRETARY THOMAS TO JOIN US SOME TIME IN

THE

NOT TOO DISTANT FUTURE.

WE LOOK FORWARD TO THAT.

BUT LET ME DO THIS, LET ME JUST OPEN THE FLOOR TO ANYBODY,

YOU

PARTICULARLY, LET ME, PERHAPS GIVE TOP PRIORITY TO THOSE OF

WHO HAVE BEEN WITH US DURING THE COURSE OF THE DAY BUT NOT

HAD

OPPORTUNITY TO GIVE TESTIMONY.

IF THERE ARE ANY OF YOU HERE WHO WOULD LIKE TO ADD YOUR

COMMENTS, RAISE YOUR HAND.

WE WILL GET A MIC OVER TO YOU.

ANYBODY AT ALL?

YES?

OVER IN THE CORNER, WE HAVE SEVERAL FOLKS OTHER HERE.

GREAT.

THANK YOU VERY MUCH.

AND IF YOU WOULD, AS WE'VE DONE IN THE FORMER TESTIMONY, IF
YOU

WOULD INTRODUCE YOURSELF, PLEASE, AS YOU BEGIN WITH YOUR
COMMENTS.

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